

Family Perspectives on Deceased Organ Donation: Thematic Synthesis of Qualitative Studies

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A major barrier to meeting the needs for organ transplantation is family refusal to give consent. This study aimed to describe the perspectives of donor families on deceased donation. We conducted a systematic review and thematic synthesis of qualitative studies. Electronic databases were searched to September 2012. From 34 studies involving 1035 participants, we identified seven themes: comprehension of sudden death (accepting finality of life, ambiguity of brain death); finding meaning in donation (altruism, letting the donor live on, fulfilling a moral obligation, easing grief); fear and suspicion (financial motivations, unwanted responsibility for death, medical mistrust); decisional conflict (pressured decision making, family consensus, internal dissonance, religious beliefs); vulnerability (valuing sensitivity and rapport, overwhelmed and disempowered); respecting the donor (honoring the donor's wishes, preserving body integrity) and needing closure (acknowledgment, regret over refusal, unresolved decisional uncertainty, feeling dismissed). Bereaved families report uncertainty about death and the donation process, emotional and cognitive burden and decisional dissonance, but can derive emotional benefit from the "lifesaving" act of donation. Strategies are needed to help families understand death in the context of donation, address anxieties about organ procurement, foster trust in the donation process, resolve insecurities in decision making and gain a sense of closure.

Keywords: Deceased donor, family, organ and tissue donation, qualitative research

Abbreviations: CINAHL, cumulative index for nursing and allied health literature; COREQ, Consolidated Criteria for Reporting Qualitative Health Research; NHS, National Health Service

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Introduction

One of the major barriers to meeting the needs for organ transplantation in more than 50 countries of the world, including the United States, the United Kingdom and Australia, is that the consent of families is required (1–3). The family consent rate is 60% (4) in the United Kingdom and 54% (5) in the United States.

Approaching grieving families with requests to donate organs from a recently deceased relative require families to make the difficult decision under very distressing circumstances (6). In spite of support for donation in principle in the general community, this is not always reflected in the actual rates of donation (7). Consent to donation is less likely when there is family conflict (8); where there is a lack of rapport with healthcare providers; where requests are ill-timed; and where families are dissatisfied with care (9–12).

Review of the families' perspectives in deceased organ donation has usually focused on the meaning of brain death and modifiable factors influencing the decisions of relatives to agree to the donation of their deceased family member's organs (13–16). We undertook a systematic review and thematic synthesis of qualitative studies of the experiences, attitudes and beliefs of families on organ donation (17). A broad understanding of family perspectives may help inform best practice service, end-of-life care and contribute to improve the donation process.

Materials and Methods

Data sources and searches

The search strategy is provided in Table S1. The searches were conducted in MEDLINE, Embase, CINAHL and PsycINFO from inception to September 3,

2012. We also searched Google Scholar, PubMed and reference lists of relevant articles and reviews. One author (AT) screened the titles and abstracts and excluded those who did not meet the inclusion criteria. Full texts of potentially relevant studies were obtained and assessed for eligibility.

Study selection

Qualitative studies that examined the perspectives of family members on deceased organ and tissue donation for transplantation were included. Studies that involved family members (parents, spouses, siblings, close relatives and friends) whose relative had died and were approached about organ donation were included. Articles were excluded if they used structured surveys, or were epidemiological studies, editorials or reviews. Non-English articles were excluded due to lack of resources for translation and limited feasibility in understanding and synthesizing cultural and linguistic nuances; and to avoid potential misinterpretation of the author's study.

Data extraction and quality assessment

For each study, we assessed the transparency of reporting as this can provide contextual details for the reader to evaluate the credibility, dependability and transferability of the study findings to their own setting. We adapted the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) framework, which included criteria relating to the research team, study methods, context of the study, analysis and interpretations (18). Authors AR and BS independently assessed each study and met regularly to resolve any differences.

Synthesis

Thematic synthesis is used to integrate the findings of multiple qualitative studies that address questions about people's perspectives and experiences. This methodology involves the translation of concepts across studies to develop descriptive and analytical themes grounded in qualitative data (17). We extracted all text under the "results/findings" or "conclusion/discussion" section of the article (17,19). These were entered verbatim into HyperRESEARCH (ResearchWare, INC.2009, version 3.0.3; Randolph, MA), software for coding textual data. To allow interpretation of data in its context and generation of analytical higher-order themes, AR performed line-by-line coding of the findings of the primary studies and identified preliminary concepts inductively by coding text that focused on family experiences and perspectives on organ donation. Similar concepts were grouped into themes. To ensure that the coding framework and themes captured all the relevant data from the primary studies, this was discussed with AT, who reviewed the articles independently. Relationships between themes were identified, examined and mapped to develop an overarching analytical framework to extend findings reported by the primary studies.

Results

Literature search and study characteristics

Our search yielded 2043 citations. Of these, 34 articles involving at least 1035 family members were included (two studies did not report the number of participants) (Figure S1). At least 672 of the families had consented to donation and 244 had not consented to donation. The study characteristics are summarized in Table 1. The studies were conducted across 13 countries listed in Table 1. Data were collected using semi-structured interviews, focus groups and open-ended surveys.

Comprehensiveness of reporting

Comprehensiveness of reporting was variable with studies reporting 6–18 out of the 27 possible items included in the COREQ framework (Table S2). Twenty-four studies reported the participant selection strategy. A description of the sample was provided in 25 studies. Almost half of the primary studies reported the use of member or investigator checking to ensure that the findings reflected the data collected. Only one study specified whether theoretical saturation was reached.

Synthesis

We identified seven themes with respective subthemes as shown in Table 2. Quotations from the studies are provided in Table 3 to illustrate each theme. The conceptual links among themes are provided in Figure 1. The positive perceptions of deceased donation delineated in the thematic schema mostly reflect data from families who consented, while the negative perceptions mostly reflect data from families who did not consent to donation. Across all themes, there was an undercurrent of vulnerability and difficulty in comprehending unexpected death. Families believed in honoring their relative's wishes to donate and thus reinforcing positive meaning in donation. For some, there was a tension between preserving the integrity of their relative's body and mistrust in the medical and organ procurement process. The importance of finding meaning in donation meant that families valued gaining a sense of closure. Decisional conflict could, however, lead to unresolved uncertainties about the decision to donate after donation.

Comprehension of Unexpected Death

Accepting finality of life

Participants struggled to accept the unexpected death of their loved one. Some doubted their relative had "died" and held hopes for their survival, and were therefore unwilling to consent to donation. They were anxious about being unable to see their relative after the donation and many did not accept they were "gone." However, participants felt better able to acknowledge death if they observed brain stem testing, received "clear, direct and progressive information about the patient's deterioration" (20) or had the opportunity to view the autopsy report or donor's body after donation.

Ambiguity of brain death

Participants sought more comprehensive information about how brain injury was defined and medically confirmed. Some could not comprehend the information and felt overwhelmed by the technical language; or reported receiving discrepant information (e.g. about time of death) from different sources, which added to their confusion and frustration. Visual aids or viewing brain stem testing helped them to better understand brain death.

Table 1: Characteristics of the included studies

Study	No*	Response rate (%)	Country	Sampling strategy	Participant relationship	Consented to donation		Number consented to donation (Y:N)	Timeframe (months)	Data collection	Methodological framework	Analysis	Topic
						Consented to donation	Number consented to donation						
Bartucci and Seller (50)	19	83	United States	Convenience	Parent of child	—	—	—	—	Open-text survey response	—	Content analysis	Responses to acknowledgment
Bartucci (32)	34	83	United States	Convenience	Parent of child	—	—	—	—	Open-text survey response	—	Content analysis	Experiences of organ donation
Bellai and Papadatou (23)	22	62	Greece	Theoretical	Parent of child	•	•	11:11	8-80	Interview	Grounded theory	Grief process	Decision making
Bellai and Papadatou (51)	22	62	Greece	Theoretical	Parent of child	•	•	11:11	8-80	Interview	Grounded theory	Grounded theory	Decision making
Carey and Forbes (22)	12	—	United Kingdom	—	Partner, child	•	—	12:0	4-2	Interview	Qualitative	Framework	Donation of corneas
Dodd-McCue et al (29)	15	8	United States	Comprehensive	Women	•	—	15:0	6-60	Focus groups	Qualitative	Thematic analysis	Role of women in donation process
Doering (30)	17	—	Canada	Random, purposive	Partner, parent, child, sibling	•	—	17:0	3-2	Interview	Gift exchange theory, social exchange theory	Content analysis	Experiences of consenting to eye donation
Haddow (28)	23	24	United Kingdom	Purposive	Partner, child, aunt, child, sibling	•	•	19:3	—	Interview	Qualitative	Thematic analysis	Communication with healthcare providers
Haddow (52)	19	33	United Kingdom	—	Partner, child, aunt, child, sibling	•	—	19:0	—	Interview	Qualitative	—	Death, embodiment, organ transplant
Jacoby et al (53)	16	16	United States	Comprehensive	—	•	•	11:5	>9	Focus groups	Qualitative	Thematic analysis	Support needs
Kesseling et al (54)	40	—	Switzerland	Purposive	Partner, parent, child, sibling, grandmother	•	•	31:9	5-7	Interview	Grounded theory	Grounded theory	Trauma, organ donation, ICU
Komers and Louw (27)	—	—	South Africa	Quota	—	•	—	—	—	Interview	Qualitative	—	Decision making
Long et al (55)	43	—	United Kingdom	Comprehensive	Partner, parent, child, sibling, cousin	•	—	43:0	0-26	Interview	Qualitative	Thematic analysis	Information sharing in hospital
López Martínez et al (20)	24	—	Spain	Purposive	Partner, parent, child, sibling, child	•	•	14:10	—	Interview	Qualitative	Discourse analysis	Process of organ donation
Manuel et al (56)	—	—	Canada	—	—	•	—	—	—	Interview	Phenomenology	Thematic analysis	Experiences of organ donation
Moraes and Massarollo (25)	8	—	Brazil	—	—	—	•	0:8	—	Interview	Phenomenology	Phenomenology	Decision making
Pelletier (6)	9	—	Canada	Comprehensive	Partner, parent, sibling	•	—	9:0	10-5	Interview	Lazarus and Folkman stress and coping theory	Content analysis	Stress in the organ donation process
Pelletier (57)	9	—	Canada	Comprehensive	Partner, parent, sibling	•	—	9:0	10-5	Interview	Lazarus and Folkman stress and coping theory	Content analysis	Coping strategies used and emotions experienced
Sanner (58)	20	91	Sweden	Comprehensive	Partner, parent, child	•	•	—	4-7	Interview	Qualitative	Thematic analysis	Experiences of organ donation

Family Views on Deceased Donation

(Continued)

Table 1: Continued

Study	No*	Response rate (%)	Country	Sampling strategy	Participant relationship	Consented to donation		Number consented to donation (Y:N)	Timeframe (months)	Data collection	Methodological framework	Analysis	Topic
						Y	N						
Shih et al (24)	22	52	Taiwan	Comprehensive	Partner, parent, sibling	•	–	22:0	6	Interview	Qualitative	Thematic analysis	Impact of organ donation
Shih et al (24)	25	29	Taiwan	Convenience	Partner, parent, sibling	•	–	25:0	0	Interview	Grounded theory	Grounded theory	Needs and expectations
Siminoff et al (26)	415	–	United States	Comprehensive	Partner, parent, child	•	•	–	2–3	Interview	Qualitative	Content analysis	Interaction with health system
Siminoff et al (59)	403	96	United States	Comprehensive	–	•	•	–	2–3	Interview	Qualitative	Content analysis	Understanding of brain death
Siminoff et al (21)	420	70	United States	Comprehensive	–	•	•	239:181	2–3	Interview	Qualitative	Content analysis	Reasons for consent
Siminoff et al (60)	420	74	United States	Comprehensive	–	•	•	–	2–3	Interview	Qualitative	Content analysis	Timing of the request for organ donation
Sque and Payne (61)	24	38	United Kingdom	Purposive	Partner, parent, child	•	–	24:0	4–36	Interview	Grounded theory	Grounded theory	Death, donation, decision making, impact of donation, perceived benefits
Sque et al (12)	49	–	United Kingdom	–	Parent, partner, child	•	•	46:3	3–26	Interview	–	Thematic analysis	Decision making
Sque et al (62)	26	–	United Kingdom	Convenience	Partner, parent, child, sibling	–	•	0:26	–	Interview	Grounded theory	Grounded theory	Reasons for nonconsent
Steed and Wager (63)	20	–	Australia	–	–	•	–	20:0	–	Interview	Qualitative	Content analysis	Bereavement process
Thomas et al (64)	17	–	Australia	Comprehensive	Partner, parent, child, sibling	•	–	17:0	2–18	Interview	Qualitative	Grounded theory	Experiences of organ donation
Tong et al (65)	13	58	Hong Kong	Convenience	Partner, parent, child, sibling	•	•	12:1	>6	Interview	Qualitative	Thematic analysis	Need, experiences, decision making
Tymstra et al (66)	15	–	The Netherlands	Random	–	•	•	8:7	12–24	Interview	Qualitative	–	Experiences of organ donation
Warren (67)	23	–	United States	Purposive	–	•	•	–	–	Interview	Phenomenology	Phenomenology	Experience of bereavement
Wilson et al (68)	77	55	Australia	Comprehensive	Partner, parent, child, sibling, friend	•	–	77:0	>12	Open-text survey response	–	–	Experiences of tissue donation

¹ augmented with Sque (69); * minimum number of participants; –, not specified; •, indicates whether or not the participants consented to donation.

Table 2: Themes

Comprehension of unexpected death
Accepting finality of life
Ambiguity of brain death
Finding meaning in donation
Saving lives
Letting the donor live on
Fulfilling a moral obligation
Easing grief
Fear and suspicion
Financial motivations
Unwanted responsibility for death
Medical mistrust
Decisional conflict
Pressured decision making
Family involvement and consensus
Internal dissonance
Adhering to religious beliefs
Vulnerability
Valuing sensitivity and rapport
Overwhelmed and disempowered
Respecting the donor
Honoring the donor's wishes
Preserving body integrity
Needing closure
Appreciating acknowledgment
Knowing recipient outcome
Unresolved decisional uncertainty
Feeling dismissed

Finding Meaning in Donation

Saving lives

Donation was perceived to improve survival and quality of life in patients requiring a transplant, and participants believed consent to donation should be given without expecting anything in return. They believed in the "goodness of organ donation" and that it was a worthwhile decision to save lives (21).

Letting the donor live on

For some participants, consenting to donation meant their loved one would continue to live on in the body of another person. They felt a sense of comfort and relief as they believed donation perpetuated their relative's "aliveness" and that their presence had not completely departed from them.

Fulfilling a moral obligation

Three studies reported that participants felt the decision to donate was instantaneous and underpinned by social duty. Participants believed that "helping ill people in society with no loss to oneself or the deceased person was the right thing to do" (22). However, others felt their decision was strongly influenced by the moral beliefs of their spouse, close friends and staff, and believed they had no choice but to consent to the donation, even when the donors' wishes were unknown, for example, in donating the organs of a child.

Easing grief

Donation was seen as a powerful diversion from grief and provided "relief, tranquility and a sense of purpose" (23) as family members focused on the positive outcome of helping someone else to live, achieved through their tragedy. There was also a perception of "donation as a cause for celebration" (22). In one study, families of younger donors believed that donation was a way to help cope with their child's death.

Fear and Suspicion

Financial motivations

In one study conducted in Taiwan, participants reported that distant family members were sceptical of their decision to donate (24). They were accused of donating to receive monetary payment for funeral expenses provided by the hospital, and felt frustrated about having to defend their decision to donate.

Unwanted responsibility for death

Participants in Brazil and Greece believed that agreeing to organ donation meant they would be consenting to the killing of their loved one or "signing their death confirmation" (25).

Medical mistrust

Some participants expressed misgivings about the health-care system. Participants in the United States, the United Kingdom, South Africa and Spain questioned the standard of medical care provided to donors and did not trust the organ donation process. Some believed that doctors had removed body parts that the family had not consented to. Participants felt reassured if healthcare providers explained the high degree of medical care they were providing to their relative. Mistrust of organ allocation was reported in the United States where African American participants believed that "rich or famous" individuals were more likely to be allocated organs than other patients (26). In another study conducted in South Africa, one family felt they were racially discriminated against and merely used to supply organs (27), and another reported a "failure of the justice and security systems" if their relative was a victim of a criminal act such as murder, and were wary their community would think they were "disposing of [the] organs contemptuously" (27).

Decisional Conflict

Pressured decision making

Often, the death of the relative was unexpected and participants described feeling a sense of "chaos," "shock" and "panic." They felt "emotionally and cognitively ill-equipped to respond" (12) to the organ donation request. The request for organ donation was sometimes felt to be

Table 3: Illustrative quotations reflecting each theme

Theme	Participants' quotations and/or authors' explanations	Contributing references
Comprehension of unexpected death Accepting finality of life	When a parent accepted the irreversibility of death he or she tended to consent to donation. (Greece) (48) For other relatives, seeing the corpse gave certainty: "Now he was really dead." (Switzerland) (51) "I needed to be sure a hundred percent that there was no chance for A to sustain life himself. And that was why I asked to be at the final brain stem test." (UK) (58) He [doctor] brought in a model of the brain with removable bits, which he took apart and showed us which bit was affected. That really put us in the picture. (UK) (52) The doctor said he had got into coma and his situation was very serious, but he had a minimum chance. In order to be sure he really had a brain death they would have to run three kinds of exams. And then he said a group of organ donation would come to talk to us. I asked: but did he die? And the doctor said no, he did not die. We found it very unusual. (Brazil) (25) No one explained exactly what the tests were or what they did to ascertain if they were dead. (UK) (58)	(6,23,25, 30-32,48,50-56, 57-59,63)
Ambiguity of brain death		(6,20,23,25,27,31, 49-53,56,58,62)
Finding meaning in donation Saving life	You help without expecting something in return, without aiming to gain something (out of the act of donation), without wanting to know who is the organ recipient. (10-year-old girl's father, donor) (Greece) (48) I was happy to hear that a young boy can now lead a normal life with a new kidney; this made the decision worthwhile. (US) (32)	(20-24,30- 32,48,49,56,58, 62,65)
Letting the donor live on	It (the donation) comforted me because although my child was buried, I was telling myself that he is still alive. What mainly helps me is to know that his heart is still beating. (2-year-old boy's mother, donor) (Greece) (23) All participants in this study believed that organ donation was a means of somehow making sure this person's memory continued. The deceased relative's existence continues in some form, and in this sense, helped keep the memory of the donor alive. (Canada) (53) Participants had other private motivations for making donations. "It's selfish really, because I wanted a bit of him to go on living you see." (UK) (58)	(20,22,23,30,32, 47-49,53,56, 58,60,61)
Fulfilling a moral obligation	I discussed it with my wife, I also discussed it with my best man and maid of honor who were at the hospital. Following these discussions, I had no other choice but to consent to the donation. (13-year-old boy's father, donor) (Greece) (48)	(22,30,48)
Easing grief	Some relatives felt it was a social duty to donate and wasteful not to. (UK) (22) I think it gives me something more to think about besides death. This has diverted my thoughts to something positive. (US) (32)	(21-23,30,32, 48,53,55,58,60, 63,65)
Fear and suspicion Financial motivations	One wife and daughter saw the donation as a cause for celebration, regarding it as a comfort and "an unexpected high in a time where things were really rock bottom." (UK) (22) For two parents, "organ donation was the only thing that gave [them] a bit of peace and comfort". (Canada) (55) It gives some meaning to an otherwise meaningless tragedy. (Australia) (60)	(24)
Unwanted responsibility for death	Relatives who were not close to us did not believe that our decision to donate organs was for others' benefits. The money provided by the hospital was not even enough for us to prepare for the funeral. Some of our relatives just did not understand this, and this really made us feel frustrated. (Taiwan) (24) He may have lived through this and I'd be the one to kill him. You see, his tiny heart was still beating. (Greece) (48) Only the brain mass died, but the rest is still alive. When you authorize the donation it seems like you are killing the person. (Brazil) (25)	(25,48)
Medical mistrust	It feels like the hospital staff is happy that someone has died from whom organs can then be harvested. (South Africa) (27)	(20,21,27-29,47)

(Continued)

Table 3: Continued

Theme	Participants' quotations and/or authors' explanations	Contributing references
Decisional conflict Pressured decision making	<p><i>How could they ask me to donate the parts (organs) of my child when I was still in such pain, when I was still crying for him? How could they expect this?</i> (South Africa) (27)</p> <p><i>It was one of the hardest moments, you want to keep on going until the end but you know you can't, either you make up your mind or the organs are lost, you are racing against time and that is the hardest part.</i> (Spain) (54)</p> <p><i>In a mess! Just one day, she passed away. The police asked me lots of questions. At that time, I was confused. Only one day!</i> I could not describe my feeling. Only chaos! Severe headache! (Hong Kong) (62)</p> <p><i>It was a decision that belonged only to me and to my spouse. Others had no right to decide for us.</i> (7-year-old girl's father, donor) (Hong Kong) (62)</p> <p><i>Organ donation is such an important issue that as a father I need to get a consensus from family members such as my wife, parents, and some close relatives.</i> (Taiwan) (31)</p> <p><i>My husband felt that donation was fine. However, my mother-in-law lost her temper. Even I didn't like her opinion, but I should respect her...Whole family persuaded her to help the other. After obtaining her permission, I made up my mind to donate.</i> (Hong Kong) (62)</p> <p><i>It was unbelievable. I see my husband lying there, well shaved, sun-tanned as he always is, breathing and breathing. It was like he was still alive!</i> (Switzerland) (51)</p>	(12,22,23,25,27,28,50,52-55,59,60,62) (63)
Family involvement and consensus	<p><i>I'm Buddhist and I think by donating her organs, her love for others can be continued and I can accumulate some credits for her to win a better afterlife. However, I can't donate her skin, otherwise, her afterlife would possibly be hurt. I mean she might become handicapped in the next human life.</i> (Taiwan) (31)</p>	(12,20,25,27,28,49,51-53,55,58-60,62,63)
Internal dissonance	<p><i>The transplant coordinator did not approach me in a hurry. All the way, she was concerned and comforted me. Both doctors and nurses were nice. They created a good atmosphere for us to consider donation.</i> (Hong Kong) (62)</p> <p>Participants in both groups (donor and nondonor) commented on the insensitive manner in which information often was conveyed to them. "It's not what you have to say. It is how you say it." (US) (50)</p> <p><i>Maybe a little bit of information would have gone a mile.</i> (US) (50)</p> <p>Family members stated that they felt "isolated," "lost" "in limbo," "disappointed because they left me up in the air," that they weren't kept up to date, "or that it "seemed to take forever" until they found out about the condition of their relative. (Australia) (61)</p> <p><i>He had two heart attacks. The doctor explained everything, but he didn't mention he was in coma, and we thought he was getting better.</i> (Brazil) (25)</p>	(6,12,22,23,25,31,3-2,47,48,50-56,59-61,64)
Adhering to religious beliefs	<p><i>My daughter always liked to take care of others... classmates, pets. I think she would agree with our decision and in this way continue to passionately help others.</i> (16-year-old girl's mother, donor) (Greece) (48)</p> <p><i>My husband had a living will that in the case of his death he wanted to donate his body... We then agree to donate his organs according to his will to honour him.</i> (Taiwan) (31)</p> <p><i>Knowing the wishes of the deceased made the process very simple.</i> (Australia) (65)</p> <p><i>I know it's not but it's too much like a butcher's shop to me. Let's have half pound of heart, three quarters of a pound of liver.</i> (UK) (49)</p> <p><i>He was my husband. You should preserve his appearance after donation. His body should be neat and tidy. I requested to check his body after the operation.</i> (Hong Kong) (62)</p>	(21,22,24,30,31,48-51,54,56,58-60,62,63)
Vulnerability Valuing sensitivity and rapport		
Overwhelmed and disempowered		
Respecting the donor Honoring the donor's wishes		
Preserving body integrity		

Table 3: Continued

Theme	Participants' quotations and/or authors' explanations	Contributing references
Needing closure	<i>Yes, when you decide to donate organs, it was awful to go through. They ask you millions of questions. Will not ever do it again. I never received one thank-you note from all those people who received his organs. You would think someone would write you a thank-you.</i> (US) (64)	(23,24,30,47,49,60-66)
Appreciating acknowledgment	<i>Knowing how thankful and appreciative they were really helped ease some of our pain.</i> (US) (47)	(23,24,32,47,49,58,60-63)
Knowing recipient outcome	<i>"For heaven's sake! I missed my son much. Is it possible for you to tell me how the recipients are doing? Can you tell me who the recipients of my child's organs are? Have they recovered smoothly? Are my daughter's organs functioning well in their new homes [bodies]?"</i> (Taiwan) (24)	
Unresolved decisional uncertainty	<i>I would never want to know if the transplant did not take, that it was all a waste.</i> (US) (32)	(60,62)
Feeling dismissed	<i>Half of the participants experienced negative emotions after the organ donation... One mother had mixed feelings about donation. She was ambivalent about whether this was a happy or unhappy deed.</i> (Hong Kong) (62)	(12,23,24,47,58,61,64,66)
	<i>We just came away from that hospital with no support, nothing, just a plastic bag with his belongings in, nowhere where you could get in touch with anyone if you needed any counselling. It's like you just walk away, empty, you know. If only they could find a nicer way of doing it than just writing a death certificate and sending you away with a plastic bag.</i> (UK) (58)	
	<i>I appreciated the care and concern of the coordinator's follow up phone calls.</i> (Australia) (65)	

UK, United Kingdom; US, United States.

poorly timed; for example, one participant reported that she was approached about consenting to donation prior to being informed about her husband's death (28). Some felt they needed more time to process the information both about the death and about the donation before making a decision.

Family involvement and consensus

For parents, the responsibility of the donation decision was viewed as belonging specifically to them. Some mothers strongly advocated that they should make the decision about donating their child's organs. Mothers believed that the close bond with their child meant they would know what their child would want. While agreement between parents was the most important, consensus among the rest of the family was also valued.

Conflicting views and tension within the family caused some participants to become anxious. Family members who believed that they were either outnumbered or overpowered by other family members felt pressure to conform. This led to distress and resentment toward their relatives. In three studies, women felt more actively involved in the decision process, and wielded a stronger influence on the decision than other members (20,29,30).

Internal dissonance

Some family members described an internal conflict between the appearance of their loved one and the confirmation of their death. Their deceased relative physically appeared "alive" and normal, particularly if they did not have visible external injuries. This created internal tension, as participants were hopeful their relative would survive yet struggled with shock and distress of having to accept death.

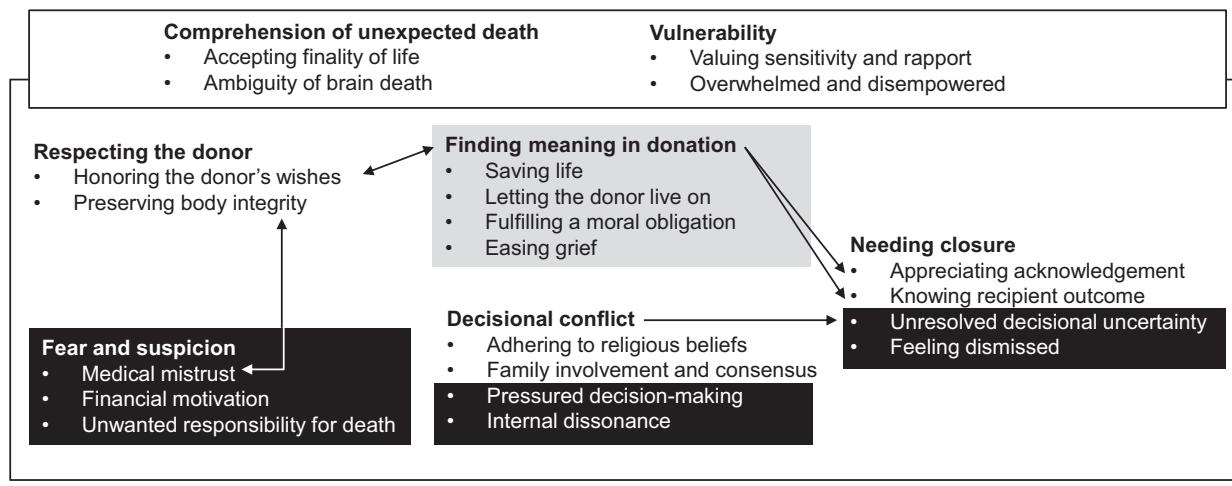
Adhering to religious beliefs

Some families were uncertain about whether their religion espoused donation and therefore felt conflicted and uncertain about donation. Some refused to consent if they believed that donation would prevent reincarnation, hinder prosperity of the family in the mortal world, disrupt the afterlife or prevent successful "re-birth" in the future. However, others believed the deceased donor would be rewarded in the afterlife for fulfilling the religious teachings of loving and helping others as well as completing one's specific mission on earth.

Vulnerability

Valuing sensitivity and rapport

Participants valued emotional support as well as sensitive and competent care given to their relative's body. They appreciated patience, sincerity and compassion from medical staff, which encouraged their decision to give consent. Others felt that some staff appeared "cold,"



Key: Positive perceptions of deceased donation
 Negative perceptions of deceased donation

Figure 1: Thematic schema. The positive perceptions of deceased donation delineated in the thematic schema mostly reflect data from families who consented, while the negative perceptions mostly reflects data from families who did not consent to donation.

"distant" and spoke in an insensitive manner and tone about their relative and therefore believed that staff treated their deceased relative as just "an object" for organ procurement.

Overwhelmed and disempowered

Being unable to access medical staff or see their relative caused frustration. Some participants described having no "rights," for example, not being allowed adequate time with their relative. They felt uninformed about their relative's condition and still held hopes that their relative was improving; then were intensely disappointed and refused to give consent when they found out, only later, the "shocking" news that their relative could not be revived.

Respecting the Donor

Honoring the donor's wishes

If participants knew their relative's decision about donation, they felt more confident about making a choice about donation. However, those who were unaware of their relative's decision or were themselves opposed to it felt hesitant and indecisive. Some believed that their relative was a kind, compassionate and generous individual who would have wanted to donate. One family consented to donation despite knowing their relative did not want to be a donor since it would benefit people in need of a transplant and was therefore justified (20).

Preserving body integrity

Some participants feared bodily mutilation, "butchering" and desecration of their relative, which they believed would

cause their relative further pain, suffering and loss of peace and protection in their afterlife. In particular, some families felt that the eyes should not be removed as they are the "window to the soul" or their relative may not be able to see God after death. Many also placed special meaning on the heart, which they believed was the "centre of the person" or the "seat of love." Some did not want to consent to donation as they were concerned about their relative's appearance and wanted the body to remain "as pretty as possible" (31).

Needing Closure

Appreciating acknowledgment

Participants who received an anonymous thank-you letter from the transplant recipient felt comforted by knowing that their decision was appreciated. This acknowledgment provided relief and reinforced their decision to consent, and instilled more "meaning" to the donation. Some participants who did not feel acknowledged expressed dissatisfaction and bitterness about the organ donation process and felt unvalued by the recipients of their relative's organs.

Knowing recipient outcome

Learning that the transplant was successful helped to validate the participants' decision to consent to donation. Families desired information about the recipients as they sought "confirmation of the value of donation, the need to extend the kinship relationship" (24) or were merely curious. One study found that Taiwanese Buddhist families and Confucian ideologists believed they would regard the

recipients as "members of their extended family" (24) while Christian donor families wanted to know about the recipient's health and quality of life. Some families attempted to locate the recipients of their relative's organs when the aforementioned information was not made available to them. On the other hand, some did not want to risk facing disappointment if they found out that the transplant had failed or was a waste (32).

Unresolved decisional uncertainty

After consenting to donation, some remained unsure about whether they had made the "right" decision and described being in an emotional limbo. Some held doubts about whether their relative had "died" and continued to feel upset and confused about the organ donation process.

Feeling dismissed

Many participants felt that there was a lack of support after the donation. Families expressed the need for specific counseling to address donation-related grief. Some participants felt empty, vulnerable, isolated or lonely after the donation, and felt "used" in order to provide their relative's organs. However, others appreciated follow-up calls from medical personnel, as they felt comforted knowing that someone else still cared.

Discussion

Family refusal to give consent contributes to the low rates of deceased organ donation observed in most countries. In our review, the positive perspective of the lifesaving act of donation was also perceived as an opportunity for the donor to "live on," and provided meaning and a sense of comfort to families. The negative aspects for the family members included coping with the unexpected death of their relative while trying to comprehend the meaning of brain death and make emotionally charged and time-pressured decisions about donation in the context of grief and bereavement. Family members valued support and acknowledgment from clinicians, while others felt vulnerable, disempowered and excluded from decision making. Some believed that their relative's body would be carelessly dismembered. Those who received acknowledgment or were told about the recipient's positive transplant outcomes after consenting to donation could gain a sense of closure, but lack of bereavement support and follow-up meant some families remained internally conflicted and uncertain about whether they had made the right decision to donate. The key insights and implications are summarized in Table S3.

Our review draws attention to differences in family perspectives on deceased organ donation across countries, cultural or healthcare environments. Across most countries, there was skepticism about whether optimal care would be provided for potential donors, though mistrust in the organ allocation system was specifically

reported by African American families in the United States (21,26). This perception may be partly driven by the striking racial disparities in access to transplantation (33–35). In South Africa, some donor families experienced discrimination, a sense of injustice, and felt they were merely used to supply organs (27). Of note, up until 2010, deceased donor kidneys in the Johannesburg region were allocated evenly between the state and private centers (36). In most Western countries, financial compensation for deceased organ donation is deemed ethically unacceptable (37). However, in Taiwan, where defraying donor medical costs and variable hospital-based financial reward occurs, there was uncertainty with families reporting that others were suspicious about how that money, if intended for funeral expenses, was actually spent (24).

Our systematic review aimed to generate a comprehensive conceptual understanding of families' perspectives on deceased organ donation, rather than to determine frequency or the strength of associations among variables and outcomes; therefore, we synthesized qualitative studies only. Qualitative studies typically use open-ended questions to elicit detailed narrative data to explain people's beliefs, attitudes and values that underpin decision making and behaviors, which may not be apparent when surveyed with prespecified variables in quantitative research. Of note, our findings complement previous quantitative studies on family's perspectives on deceased organ donation, which have found that family members are more likely to consent to donation if they know and value their deceased relative's decision to be an organ donor (16), are provided with informational support about organ donation and brain death and have complete and accurate knowledge of brain death (13,16). However, families are less likely to consent if they are not given sufficient time to make decisions, distrust medical staff, have religious fears related to donation and have communication difficulties with staff (15,16,38,39). A systematic review of observational studies and audits of modifiable factors associated with consent to donation identified lack of understanding of brain death, poor timing of the request and poor approach and skill of the individual making the request as barriers to consent (13). The thematic schema we developed extends and explains findings from previous studies by depicting the complex interplay of multiple and sometimes conflicting issues that family members, often in a state of devastation and vulnerability, consider in their decision to donate, which include respecting the donor, finding meaning in donation, fear and suspicion, family and religious values and their altruistic beliefs.

The importance of the healthcare team's communication and rapport with the family in the request for donation has been well recognized in quantitative studies (10,39,40). As found in our review, families valued sensitivity, rapport and involvement in decision making. Our findings highlight the decisional conflict in family members, which is shaped by their religious beliefs, family disagreement, urgency of the

decision and internal dissonance. Gaining a sense of closure about the donation decision is important. Families who value finding positive meaning in donation appreciate receiving acknowledgment and knowing the recipient's transplant outcomes. However, uncertainty about their decision persists in some family members after they have consented to donation.

Our systematic review methods included a comprehensive search and an independent assessment of study reporting using a standard framework (18). Software was used to code the data, thus enabling an auditable development of themes. A new comprehensive conceptual framework was developed to provide insight on the diversity of family perspectives toward deceased donation and to highlight the conceptual links among themes. However, the review has some limitations. Few participants from non-English backgrounds and ethnic minority groups were included in the primary studies as non-English articles were excluded; therefore, the transferability of the findings to these populations may be limited. Quality of reporting study methods and findings in conference abstracts of qualitative research has been found to be associated with the likelihood of publication (41); as such, publication bias is possible as we only included papers published in peer-reviewed journals. Comprehensiveness of reporting was variable across the studies, which highlights the need to improve study reporting. Also, we acknowledge the inherent social desirability bias considering that deceased donation may be a sensitive and difficult topic for participants to discuss.

The studies included in the review did not differentiate between family experiences of donation after brain death and donation after cardiac death. In some countries, donation after cardiac death has been used as a strategy to increase transplantation rates (42,43); therefore, we suggest further research focused on family perspectives on donation after cardiac death is needed.

Family members need information and emotional support when making decisions about organ donation. In many centers, the intensive care team and donor coordinator provide information and support to the donor family (44–46), although their responsibilities can vary across institutions. Giving accurate and timely information to family members about their relative's medical condition, involving family members in decision making and ensuring that families comprehend their explanation of brain death may improve satisfaction in the donation process. To address medical mistrust and suspicion, each family should have access to a donor coordinator or a healthcare provider independent of the transplant team to advocate for their needs, allay fears about body mutilation and "butchering" of the donor's body, identify and respond to anxieties and uncertainties, clarify organ allocation processes and facilitate access to bereavement counseling (46).

After the transplant surgery, family members can remain conflicted about consenting to organ donation. Usually, the donor family is informed about the transplant recipient's progress or outcome and provided with the contact details of the donor coordinator. However, our findings suggest that proactive follow-up to explicitly address and resolve internal decisional conflicts and uncertainties about their decision may promote a sense of closure, confidence and satisfaction with the donation process among donor families. This may involve offering ongoing support by the donor coordinator via follow-up phone calls for a time period that is agreed upon with the family, with personal meetings offered to families identified as vulnerable (e.g. those with less social support) as outlined in the Donor Family Care Policy published by the NHS UK Transplant (47).

Trained donation practitioners can increase family consent rates (48). Specialized training for health professionals on communicating with potential donor families would need to cover the cultural, societal and religious context that might influence the family experiences and decision making. Understanding culturally diverse family structures and values are important competencies for transplant co-coordinators and can aid in minimizing family conflict (29). As the decision to donate often involves multiple family members, we recommend a family-centered approach that considers and supports all relevant family members in the decision making and accounts for the family dynamics.

Research has focused on the donation process and consent rates but there is a relative lack of information on effective follow-up for donor families. While policies and guidelines on the care of donor families are comprehensive and address follow-up care and bereavement support in the context of organ donation, there is little research evidence about implementing these recommendations and how it impacts on families. For example, one study found that a hospital bereavement intervention program for parents after traumatic childhood death can have a positive impact on the grieving process (49). We suggest that more health services research could be conducted to evaluate, for example, specialized counseling and support groups for families who have consented to donation. Further research to identify risk factors for decisional conflict and poor psychological outcomes postdonation and to inform strategies targeted at supporting vulnerable families is also recommended.

The "lifesaving" act of donation can have a positive effect on grieving families. However, they also report an overwhelming sense of uncertainty about death and the donation process, vulnerability, an acute emotional and cognitive burden and predecisional and postdecisional dissonance. Raising awareness of the deceased donation process, as well as bereavement support strategies, is needed to help families comprehend and accept death in the context of donation, address anxieties about organ

procurement, foster trust in the donation process, resolve insecurities and tensions in their decision making and gain a sense of closure after donation. This can potentially improve family experiences and decision making in organ donation.

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Author Contributions

AT, JRC, JG, JCC, PB, KH, MI and BS contributed to the study concept and design. AR and AT collected the data. All authors drafted the manuscript and reviewed the article critically for important intellectual content.

Access to Data

AR had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of data analysis.

Disclosure

The authors of this manuscript have no conflicts of interest to disclose as described by the *American Journal of Transplantation*.

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Supporting Information

Additional Supporting Information may be found in the online version of this article.

Figure S1: Search results.

Table S1: Search strategies.

Table S2: Comprehensiveness of reporting in the included studies.

Table S3: Key insights and implications.