

**Modifiable Factors Influencing Parental Decision Making and Organ Donation:  
A Scoping Review.**

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## **Abstract**

A global shortage of organs from children and adults available for transplantation is compounded by the failure of next of the kin to consent for organs to be donated after death. There are both non-modifiable and modifiable factors which influence decision-making. Modifiable factors can though be influenced and are therefore of interest when examining families' decision making surrounding the donation of organs from their deceased child. A scoping review was undertaken to determine how modifiable factors influence parental decision-making in cadaver organ donation. Following thematic analysis two themes were identified, these were 'interaction with healthcare professionals' and 'pre-disposition to organ donation'. Satisfaction with experiences of hospital care, the information provided and the way it was communicated as well as interactions pertaining to emotional support were all found to be modifiable factors that influenced decision-making. Likewise, a predisposition to organ donation and knowing the wishes of the deceased, are highly associated with the consent decision. Nurses working in critical care environments need to be able to support parents during this difficult time. This paper therefore aims to raise awareness of modifiable factors that influence decision-making, highlighting their relevance for children's nursing practice

## **Introduction**

Obtaining consent for organ donation in children occurs at a critical and distressing period and requires sensitive management by nursing and medical staff. This article seeks to inform nurses of modifiable factors which can influence parental decision making in relation to organ donation and thereby aims to highlight measures nurses can take to support parents and families faced with this decision.

## **Background**

There is a global shortage of children's and adult organs available for transplantation. This situation is particularly detrimental to children because of the need for size matched organs (Siebelink et al. 2012) thus some children die while waiting for transplantation (Walker et al. 2013).

In the UK laws that govern organ donation are based on a voluntary opt-in system, adopting the fundamental principle of the 'dead donor rule' (Walker et al. 2013), which means that a declaration of death must take place before donation (Brierley and Larcher 2011). The Academy of Medical Royal Colleges (2008) has identified two criteria for the diagnosis of death. Firstly, irreversible cessation of brain stem function, which allows for donation after brain death (DBD), and secondly cessation of cardio-respiratory function, which allows for donation after circulatory death (DCD). In children, both DBD (heart beating donation) and DCD (non-heart beating donation) occur after withdrawal of life-sustaining support. From April 2015 to March 2016, 51 children (under 18 years of age) donated organs, 30 following DBD and 21 following DCD, representing only 4% of all donations in the UK.

Several factors seem to influence the availability of children's organs for donation. Significant advances in medicine means that children who would previously have died now survive, and improvements in accident prevention, including mandatory wearing of seat belts and wider use of helmets, has resulted in fewer children dying because of accidental death/trauma. Organs from neonates have not historically been transplanted in the UK as cessation of brain stem function in this age group is difficult to determine (Academy of Medical Royal College 2008). However, this contrasts with North American, European and Australasian practice. The Academy of Medical Royal Colleges (2015) recommended this be reviewed, and in 2015 The Royal College of Paediatrics and Child Health (RCPCH) confirmed that they were now satisfied that there is sufficient evidence to extend the criteria for diagnosis of death using neurological criteria in neonates (RCPCH 2015). Likewise, anencephalic donation (absence of the forebrain in new-born), although permitted in other countries, has only recently been recommended as 'ethically acceptable' in the UK, after death has been confirmed by circulatory criteria (Academy of Medical Royal Colleges (2015).

Vincent and Logan (2012) suggest that lack of consent is one of the single most detrimental factors affecting the conversion of potential donors to actual donors. Notably in 2013, the UK had one of the highest rates of family refusal to organ donation in the Western World (NHSBT 2013), which in 2014 stood at 41% (Allen and Hulme 2014). Although in the UK the wishes of the deceased regarding organ donation takes precedence, families can overrule their decision (NHSBT 2014) with family refusal higher when the wishes of the deceased are unknown (NHSBT 2013). It may be difficult to change some of the factors influencing the decision-making process surrounding consent, for example personal characteristics, gender, ethnicity, age and religion (Walker et al. 2013), these being termed non-modifiable factors.

Factors associated with an individual and family's beliefs and experiences are however modifiable, influenced by for example, how consent is obtained and the skill of the individual approaching the family for consent and have the potential to influence whether families donate or refuse to donate deceased relatives' organs (Vincent and Logan 2012, Simpkin et al. 2009).

Understanding how modifiable factors may influence consent is therefore of importance to children's nurses who may support families through these very complex decisions.

## **Methodology**

The review aimed to identify and map existing research which examined the extent to which modifiable factors influence parents' decision making about whether to donate their deceased child's organs. A scoping review based on Arskey & O'Malley's (2005) six-stage framework as adapted and developed by Levac et al (2010) was used (see table 1). The sixth stage of consultation was not feasible and is an acknowledged limitation of the review.

INSERT TABLE 1 NEAR HERE

## **Findings**

The preliminary search revealed a limited number of studies that specifically applied to parents of children under the age of 18 years, therefore empirical papers that examined the decision-making processes of potential adult donors were also included. Nine papers arising from eight studies were included in the final review (see Table 2). Five papers originated from the USA (Hoover et al. 2014, Jacoby and Jaccard 2010, Rodrigue et al. 2008, Rodrigue et al. 2006, Jacoby et al. 2005), two from Greece

(Bellali & Papadatou 2007, Bellali et al 2007), one from Spain (Martinez et al. 2008) and one from the UK (Sque et al.2005). Following a thematic analysis based on a framework devised by Attride-Stirling (2001), two themes, representing key modifiable factors, were identified: ‘interactions with healthcare professionals’ and pre-disposition to organ donation’. Each of these will now be discussed.

INSERT TABLE 2 NEAR HERE

### **Interaction with healthcare professionals**

Families’ interaction with healthcare professionals as a theme represents the interface with nurses and other members of the multidisciplinary team in the delivery of care. Families satisfaction with care, the information they received as part of that care and the emotional support they received were all modifiable factors that were found to influence organ donation decision-making.

#### Satisfaction with Care.

Sque at al’ (2005) undertook a quantitative study and used face to face interviews with 49 family members to identify the impact of experience of hospital care on the organ donation decision making process. They discovered that if parents held a positive view of the care provided by the healthcare team this was a precursor to consent. This was echoed in the studies by Rodrigue at al (2006, 2008) who found that satisfaction with the healthcare team was significantly higher in donor families; parents **were also more likely to consent to donation if they had a clear understanding of brain death**. Conversely, reluctance to involve families in care, and lack of encouragement to spend time with their child during end of life care decisions, was associated with families’ decisions to decline organ donation in Bellali et al’s study (2007).

Jacoby et al (2005) found that both donors and non-donors expressed similar needs during the decision-making period, including a need for emotional support in the form of consistent and frequent information about their loved one's condition, desire for compassionate and respectful care as well as having someone present who could translate difficult to understand information and ask questions on behalf of the family. There were notable differences between the donor and non-donor groups; families who chose not to allow donation were concerned with the lack of compassion shown by the staff, which led to a feeling of being alone and unsupported in their decision-making (Jacoby et al. 2005).

#### Satisfaction with Information Received

Martinez et al (2008), found that relatives who received clear unambiguous information, even though this information might have been distressing to receive, found decision making, whether refusal or agreement to donate, easier. Likewise, when information about a loved one's deterioration was clear and direct, parents could view death when it occurred, as the confirmation of an expected tragedy. Where information was not presented in this way, relatives were left with a feeling that 'more could have been done,' sometimes believing that the medical team could have intervened more in resuscitation (Martinez et al. 2008). These families were therefore less likely to donate. Likewise, Sque et al (2005) found that accurate information, supported by written and visual information, had a positive lasting effect and aided the understanding and retention of complicated information such as the concept of brain death.

Poor communication from health professionals was found by Sque et al. (2005) to be a key factor influencing families' decision to decline donation, poor communication resulting in limited knowledge and understanding of brain death an underlying factor (Sque et al. 2005). Jacoby and Jaccard (2010) observed a noticeable difference between donors and non-donors in terms of their understanding of brain death. Over three quarters of donors compared to just over half of non-donors reported that they understood the information given about brain death, with donors more likely to view the information they received as adequate and understandable. Likewise, Bellali et al (2007) reported that families experienced increased distress when the healthcare team did not explain adequately the concept of brain death and did not provide the family with information regarding their child's condition. A 'fear of body mutilation' was also a reason for refusal, which appeared to be associated with receiving limited information about the organ donation procedure (Bellali and Papadatou (2007).

### Emotional Support

Jacoby and Jaccard (2010) developed a 65-item questionnaire designed to assess the support experienced during the donation decision-making process. Three dimensions of support were measured: emotional, informational and instrumental. Emotional support included listening, providing reassurance, physical touch and demonstrating understanding, acceptance and non-abandonment. Instrumental support was concerned with maintaining comfort by meeting the physical needs of the patient; informational support related to information giving, ensuring information was understandable, families not rushed into a decision (Jacoby and Jaccard 2010:e54). In terms of emotional support, a high percentage of donor families reported that they had

been shown understanding (89%), had someone there to listen to them (84%) knew there was someone there if needed (88%) and were given hope to go on (62%), these positive responses comparably higher than those from the non-donor group.

Instrumental support appeared to have an association with organ donation; over half of donors reported that they had been provided with physical necessities such as blankets, toiletries and shower facilities, in comparison with 40% who chose not to donate. However, the strongest predictor for consent to donation was informational support, **an association between adequate and understandable information and consent to donation apparent** (Jacoby and Jaccard 2010).

### **Pre-disposition to organ donation**

Knowing the wishes of the deceased and their and their families pre-disposition to organ donation, were recurrent factors in the studies reviewed, these factors influencing decision-making. Hoover et al (2014) used qualitative research to describe 13 parents' experiences during the decision-making process of DCD. The researchers found that honouring the deceased child's preference was an important criterion in the decision. Those who agreed to donation held a belief that their child would have wanted to help others, findings that were also apparent in Bellali & Papadatou's (2007) study.

Martinez et al (2008) found that both the deceased's intention to donate and families' positive view on organ donation, acquired prior to hospital admission, were the main factors in families' decision making. Similarly, the wishes of the deceased were an important criterion in refusing the donation (Martinez et al. 2008). Similar findings were identified in Rodrigue et al's (2006) study; an expressed intention to donate organs by the deceased, both in the form of a donor card and verbally, was

significantly associated with consent. Indeed, this was the most important factor for the next of kin in the decision-making process, findings also evident in other studies reviewed (Rodrigue et al 2008, Jacoby and Jaccard 2010). Rodrigue et al (2008) also found an association between holding donor registration as a parent and consent to donation on behalf of their child.

Limited prior discussion regarding organ donation is associated with non-donation. Bellali & Papadatou (2007) and Bellali et al (2007) found that parents who lacked knowledge on the topic of organ donation, or who were unaware of their church's position, experienced difficulties in the donation making process and were likely to decline the donation. However, the researchers also observed that donor parents were influenced by altruistic motives, the decision to donate reflecting parents' perceptions of their child's nature/desire to help others (Bellali & Papadatou 2007).

## **Discussion**

Families who face decisions regarding organ donation do so during a highly charged and emotional period, decisions which are heightened for all concerned when the potential donor is a child. The approach of staff caring for the family at this time is a key modifiable factor as it is apparent from the review that a link between permission to donate and perceptions of care exist. Perceptions of quality of care are interlinked with the quality and timing of information, both of which serve to enhance the families' trust in healthcare professionals. The concept of brain death is difficult to understand and yet families are often presented with this information at a critical period. Research indicates that the skills of the health care professional when providing specific information is a key modifiable factor which can improve organ donation rates (Vincent & Logan 2012), with parental knowledge of brain death

positively associated with organ donation (Rodriguez et al 2008). Improvements in the way information is communicated including the use of visual aids could aid understanding of brain death, the organ donation process and fears of body mutilation, all of which were associated with non-donation in the papers reviewed.

Knowing the deceased's wishes and being pre-disposed to organ donation prior to hospital admission are key modifiable which influence families' decision-making, this finding evident in this review and the wider literature (Vincent and Logan 2012, Smith et al. 2008, Exley et al. 2002, Martinez et al. 2001). However, as it is more difficult for children to express their wishes due to their age or lack of competence, promoting positive attitudes towards organ donation is essential. Walker et al (2013) propose that educational interventions associated with prior preparation could increase donation consent rates. The programmes need to challenge misconceptions, and address some of the challenges faced when making decisions on behalf of a child or young person, addressing cultural attitudes and beliefs (Walker et al 2013). Walker et al (2013) propose that by challenging misconceptions, and addressing some of the challenges faced when making decisions on behalf of a child or young person, educational interventions could decrease families' anxiety about organ donation, programmes also addressing cultural attitudes and beliefs (Walker et al 2013).

The need for education of the public was a consistent recommendation arising from the reviewed studies. Raising of public awareness and knowledge may help to overcome fears and concerns, stimulate family conversations, promote positive attitudes towards organ donation and alleviate the element of surprise when approached. Although much has been done in the UK to raise awareness of organ donation, not enough emphasis has been placed on paediatric donations. Emphasis

should be placed on educating children and young people regarding organ donation to encourage discussion about their wishes with their parents (Transplant 2013).

Additionally, educating the public on the shortage of organs and promoting positive outcomes after transplantations could be beneficial (Mercer 2013).

### **Implications for Practice**

Nurses are in a unique position in their relationships with patients and families, involved in and sharing what are likely to be both emotional highs and lows, represented in for example the acquisition of a donor organ after many months of waiting, or, alternatively, witnessing the perhaps sudden and unexpected death of a child, leading to discussion surrounding organ donation. It is imperative that nurses do not pressurise parents, as family members' who feel pressurised to make decisions regarding donation are less likely to donate (Sque et al 2005); instead, nurses should be available to answer families' question honestly and transparently, supporting them irrespective of the final decision made. Having clear, pre-prepared, written and or visual information about brain death and the donation process (Bellali & Papadatou 2007), that has been reviewed by families to assess suitability, could allow families to independently digest information and may be of benefit. Effective communication may also help to alleviate the fear of body mutilation and confusion about the viability of organs (Transplant 2013, Hoover et al. 2014, Bellali & Papadatou 2007).

It was evident from the papers reviewed that quality of care has been highly associated with consent to donate. Being attentive to parents, forming a supportive and trusting relationship, respectful and compassionate care and encouraging parental presence at the potential donor's bedside were among the needs identified by families and directly related with the perception of quality of care. All the above form the basis

of the values and principles of good nursing care and are reflected in NMC Code of Conduct (2015).

## **Conclusion**

Children's nurses have the potential to influence organ donation decisions. At a fundamental level providing compassionate care grounded in open and honest communication with parents and their wider families is an essential requisite. Simple measures, such as providing for the physical needs of parents including provision of toiletries and blankets, will, as noted in the findings of the review, also have a positive impact on parental decision making (Jacoby and Jaccard 2010).

Nurses have an important role in public education, as they can initiate discussions regarding organ donation with families in health care settings. Indeed, research indicates that, in contrast to adult organ donation, **parents value the involvement of paediatricians, nurses and other health professionals in decisions about organ donation, and are more likely to agree to donation if a member of their child's health care team discusses options with them (Rodriquez 2008).** Consequently, children's nurses and other healthcare professionals, especially those working in critical care settings, would benefit from training and education on the organ donation process and end of life care, including the criteria for determining brain death. Training should also raise awareness of modifiable factors and thus how nurses' approach to families can influence decision-making (Jacoby & Jaccars 2010, Bellali et al. 2007, Sque et al. 2005, NHSBT 2013), subjects which should be included in training programmes for both nurses and doctors working with children and young people.

## References

Academy of Medical Royal Colleges. (2008). *A code of practice for the diagnosis and confirmation of death* PPG Design and Print LTD

Academy of Medical Royal Colleges. (2015). *Ethical issues in paediatric organ donation a position paper by the UK Donation Ethics Committee*

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International journal of social research methodology*, 8(1), 19-32.

Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative research*, 1(3), 385-405.

Aveyard, H. (2014). *Doing a Literature Review in Health and Social Care a Practical guide*. Open University Press

Bellali, T., & Papadatou, D. (2007). The decision-making process of parents regarding organ donation of their brain dead child: A Greek study. *Social science & medicine*, 64(2), 439-450.

Bellali, T., Papazoglou, I., & Papadatou, D. (2007). Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation. *Intensive and critical care nursing*, 23(4), 216-225.

Brierley, J., & Larcher, V. (2011). Organ donation from children: time for legal, ethical and cultural change. *Acta Paediatrica*, 100(9), 1175-1179.

Exley, M., White, N., & Martin, J. H. (2002). Why families say no to organ donation. *Critical Care Nurse*, 22(6), 44-51.

- Garrard, J. (2007). *Health Sciences Literature Review Made Easy The Matrix Method*. Jones and Barlett Publishers.
- Hoover, S. M., Bratton, S. L., Roach, E., & Olson, L. M. (2014). Parental experiences and recommendations in donation after circulatory determination of death\*. *Pediatric Critical Care Medicine, 15*(2), 105-111.
- Jacoby, L., & Jaccard, J. (2010). Perceived support among families deciding about organ donation for their loved ones: donor vs nondonor next of kin. *American Journal of Critical Care, 19*(5), e52-e61.
- Jacoby, L. H., Breitkopf, C. R., & Pease, E. A. (2005). A qualitative examination of the needs of families faced with the option of organ donation. *Dimensions of Critical Care Nursing, 24*(4), 183-189.
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implement Sci, 5*(1), 1-9.
- Martínez, J. M., Lopez, J. S., Martín, A., Martín, M. J., Scandroglio, B., & Martín, J. M. (2001). Organ donation and family decision-making within the Spanish donation system. *Social science & medicine, 53*(4), 405-421.
- Martínez, J. S. L., López, M. J. M., Scandroglio, B., & García, J. M. M. (2008). Family perception of the process of organ donation. Qualitative psychosocial analysis of the subjective interpretation of donor and nondonor families. *The Spanish journal of psychology, 11*(01), 125-136.
- Mercer, L. (2013). Improving the rates of organ donation for transplantation. *Nursing Standard, 27*(26), 35-40.

Moule, P., Goodman, M. (2014). *Nursing Research An Introduction*. Sage Publications LTD.

NHSBT, (2013). Taking Organ Transplantation to 2020 A detailed strategy (online) last accessed on 20.03.2015 at [http://www.nhsbt.nhs.uk/to2020/resources/nhsbt\\_organ\\_donor\\_strategy\\_long.pdf](http://www.nhsbt.nhs.uk/to2020/resources/nhsbt_organ_donor_strategy_long.pdf)

NHSBT, (2016). Organ Donation activity. Last accessed on 29.10.2016 at [http://www.odt.nhs.uk/pdf/activity-report/organ\\_donation\\_activity.pdf](http://www.odt.nhs.uk/pdf/activity-report/organ_donation_activity.pdf)

Rodrigue, J. R., Cornell, D. L., & Howard, R. J. (2006). Organ donation decision: comparison of donor and nondonor families. *American Journal of Transplantation*, 6(1), 190-198.

Rodrigue, J. R., Cornell, D. L., & Howard, R. J. (2008). Pediatric organ donation: what factors most influence parents' donation decisions?. *Pediatric critical care medicine: a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies*, 9(2), 180.

Royal College of Paediatrics and Child Health (RCPCH 2015) Criteria for diagnosing death in infants less than 2 months of age published (online) last accessed 29.10.2016 at <http://www.rcpch.ac.uk/news/criteria-diagnosing-death-infants-less-2-months-age-published>

Siebelink, M. J., Albers, M. J., Roodbol, P. F., & van de Wiel, H. (2012). Key factors in paediatric organ and tissue donation: an overview of literature in a chronological working model. *Transplant International*, 25(3), 265-271.

Simpkin, A. L., Robertson, L. C., Barber, V. S., & Young, J. D. (2009). Modifiable factors influencing relatives' decision to offer organ donation: systematic review.

Smith, S. W., Massi Lindsey, L. L., Kopfman, J. E., Yoo, J., & Morrison, K. (2008). Predictors of engaging in family discussion about organ donation and getting organ donor cards witnessed. *Health communication, 23*(2), 142-152.

Sque, M., Long, T., & Payne, S. (2005, March). Organ donation: key factors influencing families' decision-making. In *Transplantation proceedings* (Vol. 37, No. 2, pp. 543-546). Elsevier.

Transplant. (2013). Increasing Consent for Organ Donation in the UK (online) last accessed on 20.04.2015 at [http://www.kidney.org.uk/documentlibrary/Transplant13-Increasing\\_Consent.pdf](http://www.kidney.org.uk/documentlibrary/Transplant13-Increasing_Consent.pdf)

Walker, W., Broderick, A., & Sque, M. (2013). Factors Influencing Bereaved Families' Decisions About Organ Donation An Integrative Literature Review. *Western journal of nursing research, 0193945913484987*.

Vincent, A., & Logan, L. (2012). Consent for organ donation. *British journal of anaesthesia, 108*(suppl 1), i80-i87.

**Table 1: Stages of the Scoping Review. Adapted from Levac et al (2010) and Arskey & O'Malley (2005).**

<b>Stage</b>	<b>Associated Activities.</b>	<b>As Applied to this Review</b>
1. Identifying the research question	<ul style="list-style-type: none"> <li>a) Decide what's important to give a clear rationale for undertaking the study.</li> <li>b) Devise broad research question(s)</li> <li>c) Decide search parameters.</li> </ul>	<ul style="list-style-type: none"> <li>a) Modifiable factors can influence decision-making in relation to organ donation</li> <li>b) Do modifiable factors influence parental decision-making regarding the donation of their deceased child's organ(s)?</li> <li>c) Research that examines parental experiences of consenting (or refusing to consent) to donation of their deceased child's organ(s). Following a brief analysis of literature on organ donation, key search terms were generated). The final search terms and combinations used were: 'p#diatric or child*' and 'organ donation' and 'parent* or famil*' and 'consent or decision' and 'influenc*' and 'factors'.</li> </ul>
2. Identifying relevant studies	<ul style="list-style-type: none"> <li>a) Search a comprehensive range of sources including, databases, reference lists, hand searching key journals, existing networks, relevant organisations and conferences.</li> <li>b) Decide time span, and language.</li> <li>c) Justify decisions made about scope based on feasibility (time and resources) versus need to address the research question or study purpose</li> </ul>	<ul style="list-style-type: none"> <li>a) EBSCO host databases were searched, giving access to Academic Search Premier, MEDLINE, Psychology and Behavioral Sciences Collection, PsycINFO, SPORTDiscus and CINAHL Plus with Full Text. Reference lists of the key articles were then reviewed and the 'related articles' and 'cited by' option in Google Scholar used to identify further relevant research papers.</li> <li>b) To locate contemporary studies a time limit of five years was initially used as a search parameter, however this yielded a low number of papers, therefore the time limit was extended to 10 years (2005-2015). Only papers published in English were retrieved.</li> <li>c) The parameters of the review were feasible for the resources allocated; the review was undertaken over a nine-month period.</li> </ul>

3. Study selection	<p>a) Identify study inclusion and exclusion criteria</p> <p>b) Criteria applied to abstracts retrieved through search strategy.</p> <p>c) Reading of studies meeting the inclusion criteria to confirm inclusion in the review, adopting a team approach to decision making.</p>	<p>a) Study inclusion and exclusion criteria</p> <ul style="list-style-type: none"> <li>• Primary research.</li> <li>• Research that explored parents'/families' experiences and factors influencing consent or refusal of organ donation of their deceased children/relatives.</li> <li>• Decisions concerning donation after circulatory and brain death</li> <li>• Papers that only discussed non-modifiable factors such as the personal beliefs of the next of kin and the perceptions of healthcare professionals were excluded.</li> </ul> <p>b) Abstracts were screened using the above inclusion criteria: The search initially generated 68 papers, following review of abstracts six papers met the inclusion criteria. An additional two research papers were identified following up the reference lists and one article was located using Google Scholar.</p> <p>c) KL undertook the search, retrieved papers and screened abstracts. Both authors independently read the papers to determine suitability for inclusion. Decisions about inclusion in the review were made independently by both authors and jointly corroborated</p>
4. Charting the data	<p>a) Sift and sort the material as an iterative process, deciding what information to record and how</p> <p>b) Assess methodological quality of studies included</p> <p>c) Summarise process information</p>	<p>a) The key data were extracted and summarised by KL using a matrix tool adapted from Garrard (2007); KC undertook a further independent review.</p> <p>b) The Critical Appraisal Skills Programme (CASP) frameworks were used to develop a consistent approach to the appraisal of the research studies selected (Aveyard 2014).</p> <p>c) Process information summarised using (see Table 2).</p>
5. Collating, summarising and reporting the results	<p>a) Undertake a thematic/content analysis</p> <p>b) Present a narrative account of findings</p> <p>c) Organise literature either thematically, through a framework or table of strengths and weaknesses.</p>	<p>a) Principles as outlined by Attride-Stirling (2001), adopted for thematic analysis</p> <p>b) See Paper</p> <p>c) Literature organised thematically – see paper.</p>

**Table 2. Summary of Studies Included in Review.**

Author(s)	Purpose of Study	Sample	Methodology	Findings
Bellali T et al. (2007)	To describe parental challenges throughout the organ donation decision and to provide evidence based recommendations for nurses and healthcare professionals for effective introduction of the subject and support for families.	Purposive sample; 22 Greek bereaved parents of 14 underage brain dead children	Part of a larger study on parental bereavement. Qualitative study with data collection via semi structured interviews conducted separately with each parent.	Parents' decision-making process was described as challenging and fraught with difficulties both before and after the donation period. Challenges were clustered into three areas (a) <i>personal challenges</i> , (b) <i>conditions of organ request</i> , and (c) <i>interpersonal challenges</i> . Parents' main concern following donation was the lack of information about transplantation outcomes.
Bellali T & Papadatou. D. (2007)	To explore the decision-making process of parents faced with the organ donation decision of their brain-dead child and identify which factors affect consent or refusal.	Purposive sample; 22 Greek bereaved parents of 14 underage brain dead children	Part of a larger study on parental bereavement. Qualitative study with data collection via semi structured interviews conducted separately with each parent	Factors that influenced parents' decisions were identified and classified into (a) personal factors, (b) conditions of organ request, (c) parents' prior knowledge and experience with organ donation or serious illness, and (d) interpersonal factors.
Hoover SM et al. (2014)	To describe parents' experience of organ donation decision making in the case of donation after circulatory death.	Convenience sample from a single children's hospital. 11 families (13 parents; 11 donors, 2 non-donors)	Qualitative analysis with data collection via interviews with individual parents	Honouring the deceased's preferences and confusion about medical viability of the organs were identified as the modifiable factors that influenced parental decision.

Author(s)	Purpose of Study	Sample	Methodology	Findings
Jacoby et al. (2005)	To examine perceived needs for support of donor and non-donor families	98 potential participants identified through record review at 3 organ procurement organizations and contacted via a telephone call. Final sample n= 16 (11 donors, five non-donors)	Qualitative study using focus group methodology	Donor and non-donor families both expressed the need for clear information, consistent emotional support and presence of someone who could act as a 'translator,' mediating between the families and healthcare professional. Some non-donor families said that the unmet need for compassionate and respectful care of their loved one influenced their decision to decline the donation request. Non-donor, as families, identified poor timing and inappropriate request as factors influencing their decision to decline the donation.
Jacoby L and Jaccard J (2010)	To (1) obtain accounts from family members of support received and their perceptions of quality of care for themselves and their loved ones when making the donation decision, and (2) to examine the relationship between these factors and the families' donation decision.	326 persons approached via a letter and a follow-up phone call. Final sample n= 199 (154 donors, 45 non-donors).	Retrospective survey using telephone interviews of 199 families	African American families were less likely to consent than White. Differing perceptions of quality of care were evident between donor and non-donor families Receiving understandable information about organ donation was the strongest predictor of consent.
Martinez et al. (2008)	a) To identify the principle psychosocial variables that affect the decision process of granting or denying permission of organ donation by family members who are directly involved; b) to analyze the interaction of these variables during the process of organ donation; and (c) to propose a model of decision process that can be contrasted by means of quantitative and qualitative methodology.	Purposive sample chosen by organ donation coordinators according to given protocol. Six families who had received the request to donate the organs of a deceased relative	Discourse analysis of semi-structured interviews using "The Family Organ Donation Interview" instrument	The main factor influencing donation decision were knowing the deceased's intention to donate and families' positive view on organ donation acquired prior to hospital admission.

Author(s)	Purpose of Study	Sample	Methodology	Findings
Rodrigue et al. (2006)	To examine the relative influence of donor and next-of-kin factors, requestor characteristics, communication processes and satisfaction with the health care team on the donation decision	Purposive sample of 285 next-of-kin of donor-eligible deceased individuals who had been approached by coordinators from one organ procurement organization (OPO) in the southeastern USA from July 2001 to February 2004.	Telephone survey using a structured questionnaire; data subjected to univariate and multivariate analyses and logistic regression	Several factors influenced organ donation decisions: being white, younger in age, having made organ donation intentions known and favourable attitudes towards organ donation amongst family members all had a positive association with organ donation. Additionally, being approached about donation by an OPO coordinator, the requestor sensitive to families' needs and the timing of the request perceived as optimal also positively influenced donation decisions. Findings highlight the need for continued public education efforts to maximize positive beliefs about organ donation, to share and document donation decisions and to improve communication processes.
Rodrigue JR et al. (2008)	To identify factors that influence parental decision-making when asked to donate a deceased child's organs	Seventy-four parents (49 donors, 25 non-donors) of donor-eligible deceased children who were previously approached by coordinators from one organ procurement organization (OPO) in the southeastern USA	Cross-sectional design with data collection via structured telephone interviews.	Multivariate analyses demonstrated that organ donation was more likely when the parent was a registered organ donor, had favorable organ donation beliefs, and was exposed to organ donation information prior to the child's death. The approach of the child's healthcare team when organ donation is first mentioned, the requestor perceived as sensitive to the family's needs, and the family/family members having sufficient time to discuss and agree donation all had a positive impact.
Sque M et al. (2005)	To clarify the decision-making and bereavement needs of family members who had organ donation discussed with them; to provide a rationale for further preparation of professionals involved in this sensitive work.	A purposive sample of 49 family members who had donation discussed with them, were recruited at 3 to 5, 13 to 15, and 18 to 26 months' post bereavement	A 3-year longitudinal design. Face-to-face interviews and two, self-completed; psychometric measures, the Beck Depression Inventory II and the Grief Experience Inventory, were used with participants who chose to donate. Single interviews were carried out with participants who declined donation.	Four main categories explained the factors that influence families' decision-making process: concerns about knowledge of the deceased's donation wish; views held by the extended family about donation; giving meaning to the death and events that occurred in the hospital that were perceived as positive or negative; children's role in the decision-making process.

