

Supplementary File 1.

Method used to calculate citation-linked impact scores

For each source, an *outgoing citations* score was calculated by counting the number of sources that it cited for each time period that it could cite (for example, T4 sources could cite sources from T1 through to T4, while T2 sources could only cite T1 or T2 sources). If five or more sources from a specific time period were cited by a source, an outgoing score of five was given for that time period, while the number of outgoing citations to a particular period was used as the score for that time period if it was less than 5. After scores for the different time periods were added together, the total outgoing citations score for a source was capped at a maximum of 3 x (Number of periods it could cite). In other words, T4 sources could receive a maximum of 12 (3 points x 4 periods) for citations made. Using this method, citing sources from various time periods contributed to a higher citation score than only citing the most recent sources.

Where the source was cited by other sources from amongst the 120 sources selected by Dicks et al. (2017), the total number of *incoming citations* from those sources was added to the outgoing citations score to produce a citation-linked *impact score*. In this way, being cited by another article carried more weight than citing numerous sources, and the impact score is a measure of the source's activity specifically within the system created by the selected sources. These impact scores were ranked per time period so that sources could be compared to others from the same period. They were then sorted into quartiles, with the lowest scoring sources being allocated a scaled score of zero, and the highest scoring quartile receiving a scaled score of 3. Supplementary Table 1 demonstrates this using 6 sources from T3. The numbers in brackets related to Manuel et al. (2010) show the moderating of high out-going citation scores as described earlier.

As demonstrated by Supplementary Table 1, Kesselring et al. (2007) and Siminoff et al. (2001) contributed significantly to the sharing of information in the field of organ donation. The studies of Frid et al. (2007) and Tavakoli et al.

(2008) contribute valuable information to the understanding of family bereavement specifically, but that information has not been effectively shared.

Supplementary Table 1. Demonstration of determination of local impact based on citations

Source	Time period	Cites T1	Cites T2	Cites T3	Outgoing	Incoming	Impact score	Scale score
Frid et al. (2007)	3	0	0	1	1	1	2	0
Tavakoli et al. (2008)	3	0	1	3	4	1	5	1
Manuel et al. (2010)	3	3	11 (5)	7 (5)	13 (9)	9	18	3
Kesselring et al. (2007)	3	0	2	5	7	23	30	3
Siminoff et al. (2001)	3	0	4	0	4	31	35	3

Method used to calculate Combined (relevance and citations) impact score

After completion of the review of family bereavement experiences (Dicks et al. 2017), the role that sources played in the formulation of that specific review could be determined. Each source’s contribution to five key sections of the review (covering events at the hospital, aftercare, and ongoing bereavement) was determined. A source was given one point for each section that it contributed to, and the total score (max=5) was added to the citation-linked impact scores. This produced a combined impact score that considered both the source’s level of citation activity, and how relevant content was to the understanding of family bereavement. Sources were then ranked per time period to determine the “Top 3” sources for each period.

Supplementary Table 2. Summary of research priorities identified

Theoretical considerations

Related to systems theory

Describe interaction between sudden death, trauma, a donation request, and

ongoing bereavement

The experiences of individual family members and the family as a whole should be explored

Aim to understand outcomes and the mechanisms contributing to those outcomes

Development of theory

There is a need for a holistic theoretical model of this context incorporating grief theory

Overarching focus of research related to families

Explore the psycho-social experiences and needs of families in a holistic way including the time in the hospital and time after returning home to improve in-hospital and aftercare services

Specific factors

Research should explore vulnerability, family satisfaction, fostering family empowerment, and facilitating healthy bereavement experiences, as well as pre-existing family relationships, the donation pathway (DCD or DBD), culture, religion, demographic factors, trust, and hope

Identify the influence of risk factors and protective factors on family bereavement

Explore the needs of families who initiate discussions about donation with staff, young people and children, and the relationship between donating families and transplant recipients

Investigate how education campaigns can prepare families for the in-hospital process

Methodological considerations

Research relationships

Researchers must develop collaborative partnerships with stakeholders including family members and Ethics Committees, and establish advisory panels to guide decision-making about research

Overall study design

Prospective qualitative longitudinal studies can capture data about dynamics and changes over time

Multi-centre studies will produce findings that are transferable

Recruitment and data collection

Recruitment processes must be carefully considered in this sensitive context.

Early recruitment may contribute to better recall but must be balanced with support and care.

Interview guides should allow for flexibility according to family needs rather than being too rigid

A conversational interview style and caring presence is preferred by families

Preparation of the researcher

Sensitive research with recruitment challenges suggests provision be made for secondary analysis

Because participants may ask questions to clarify misunderstandings, researchers should have knowledge of general processes and refer families to staff who can answer more specific questions

Provide opportunities for participants to comment on the research and data analysis

Researchers should reflect on the way that they contribute to participants' stories as they narrate / report on research findings, and they should aim to accurately represent the voices of participants

Dissemination

Apart from conducting good research, researchers must efficiently disseminate findings.

Practice improvement

Collaborative working relationships with stakeholders in the hospital environment can contribute to findings being used in training workshops which would foster practice improvement.

Creative feedback loops need to be established to allow families who have experienced the donation context to share information with “new” families as they encounter in-hospital processes

Research related to staff

The relationship between family and staff and the support needs of staff must be explored

Training of staff must include attention to technical and interpersonal competencies

The capacity of donation and hospital staff to conduct research should be enhanced
