

# In-hospital experiences of families of potential organ donors: A systematic review and qualitative synthesis

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## Abstract

Information and compassion assist families of potential organ donors to make informed decisions. However, psychological implications of the in-hospital process are not well described with past research focusing on decision-making. To enhance understanding and improve service delivery, a systematic review was conducted. Inductive analysis and synthesis utilised Grounded Theory Methodology within a systems theory framework and contributed to a model proposing that family and staff form a System of Systems with shared responsibility for process outcomes. This model can guide evaluation and improvement of care and will be tested by means of a longitudinal study of family experiences.

## Keywords

acute grief, family-centred care, family empowerment, health care systems, making a decision about donation, organ donation, perseverance, systematic review

## Introduction

Family experiences at the time of a potential organ donation include stress following a traumatic event (Ralph et al., 2014), anticipatory mourning (Holtkamp, 2000), accepting death and deciding about donation. Grieving begins at the hospital (Sque et al., 2003), and initial experiences have a lasting impact on bereavement (Walker and Sque, 2016).

Complex relationships exist between variables of the in-hospital process (Walker et al., 2013), and studies highlight the need for a comprehensive understanding of the experience (Falomir-Pichastor et al., 2013). However, although a number of studies have explored ways of assisting families to make an informed decision about donation, provision of grief support and identifying ways of assisting families to commence their bereavement meaningfully have received less attention (De Groot et al., 2012).

Increased understanding of family experiences during the in-hospital process will assist staff to address needs, evaluate service provision and improve procedures (De Groot et al., 2012; Walker et al., 2013). In addition,

understanding of the in-hospital process will contribute to understanding of how that process is linked to grieving.

## Research question

What are the experiences of families during the in-hospital process after identification of a potential organ donor?

## Aims

The aims of the study are, first, to gain a holistic, evidence-based understanding of family experiences at the time of a potential organ donation, and second, to identify leverage points that could contribute to enhanced care and family empowerment at the beginning of their bereavement.

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**Table 1.** Details of electronic search.

Line	Search string
1	(psychological or social or option or grief or grieve or grieving or bereaved or needs or bereavement or support or consent or decide or decision or experience\$)
2	(brain or brainstem or circulatory or cardiac) AND (death)
3	(palliative or allocation or intervention or process or procure or procurement or procuring or transplant or transplantation or DCD or BD or post-mortem or cadaver or pre-mortem or posthumous or deceased or potential)
4	(family or families or relative or relatives or parent or parents or parental) AND (organ) AND (donation or donor or donate or donors)
5	(databases or Cochrane or Medline or Pubmed or Cinhal or Cinahl or Psyc\$info or Embase or Elsevier)
6	TI (systematic* or narrative or integrative or ethical or theoretical or literature or comprehensive or review or overview)
7	(1 OR 2 OR 3) AND 4 AND (5 OR 6)
8	Date: 2005–2016 Language: English

BD: brain death; DCD: donation after circulatory death.

## Method

### Data collection

On 10 December 2016, an electronic search of the PsycINFO, Academic Search Complete, CINAHL, MEDLINE, PsycARTICLES and Psychology and Behavioral Sciences Collection databases was conducted using the strategy described in Table 1. Cochrane Library, Campbell Collaboration Library, Centre for Reviews and Dissemination, *Systematic Reviews Journal*, books and reference lists were searched during December 2016.

### Inclusion and exclusion criteria

English reviews published between 2005 and 2016 that systematically combined findings of studies addressing psychosocial experiences of families at the time of a potential organ donation were included. Articles that are not systematic reviews or are related to the general population, education campaigns, public attitudes or legislation were excluded.

### Data evaluation

The 27-item PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) (Moher et al., 2009) and the 11-item AMSTAR (assessment of multiple systematic reviews) (Shea et al., 2009) checklists assessed reporting standards and methodological quality, respectively.

### Data analysis and synthesis

Reviews were analysed without using software. Descriptions of family experiences were extracted and coded simultaneously based on the *Grounded Theory Literature Review Method* described by Wolfswinkel et al. (2013). Thereafter, codes were categorised and relationships within and between categories were explored.

## Results

A systematic search for systematic reviews (Smith et al., 2011) was conducted to illuminate the in-hospital experiences of families of potential organ donors. Electronic searching identified 717 articles, and hand-searching another six. After removing duplicates and screening titles and abstracts, 25 articles remained. Full text copies were assessed and seven reviews met inclusion criteria. Of these, six had been identified by the electronic search and one is a book chapter (see Figure 1).

Because family experience is connected to staff activity, Anker's (2013) review of requester communication and Mills and Kouloughlioti's (2016) exploration of nursing support were included. Falomir-Pichastor et al.'s (2013) exploration of pre-existing factors is also relevant and describes how these factors influence the in-hospital experience. Anker (2013) and Falomir-Pichastor et al. (2013) did not follow PRISMA reporting standards, lowering PRISMA scores. Anker's (2013) review also scored lower on the AMSTAR checklist. Nevertheless, these articles make a valuable contribution to the study.

The reviews approached the context from different vantage points contributing to multi-disciplinary descriptions and diversity, enhancing depth. Table 2 summarises features of the selected reviews, while Table 3 summarises the main findings of the reviews.

## Findings

Analysis identified the core categories of pre-existing factors and future-oriented considerations, provision of care, resources and risks and attending to tasks.

### Pre-existing factors and future-oriented considerations

Walker et al. (2013) describe pre-existing and future-oriented factors that influence family experiences.

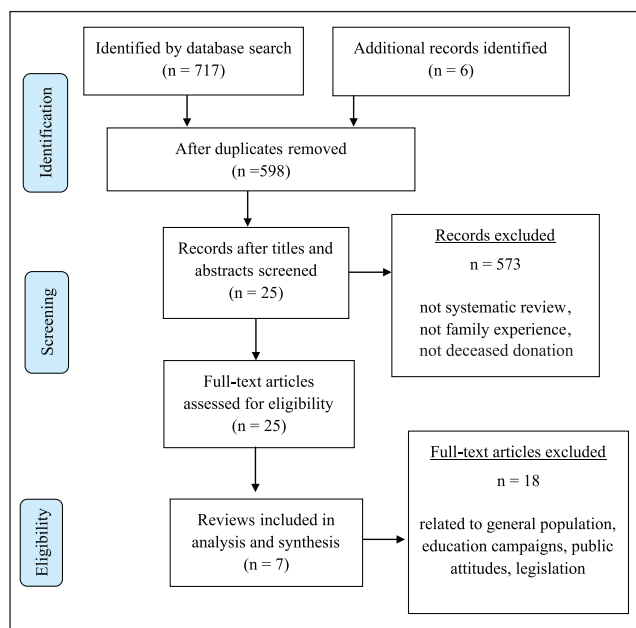
Pre-existing *family dynamics* influence family unity, and the *pre-existing relationship with the deceased* will influence each family member's reaction to their death (Ralph et al., 2014). Falomir-Pichastor et al. (2013) identified factors contributing to *attitudes* about donation. Individuals may speak about their attitudes, register their

preferences or take no action. In hospital, *knowledge and inferences* about the deceased's and family members' preferences influence family experience (Falomir-Pichastor et al., 2013). *Cause of death* is important too, and Walker et al. (2013) described intense emotional responses to sudden death.

Some future-oriented factors relate to the *potential for donation*, such as relieving suffering of others or ensuring that something good comes from the family's loss. Other factors focus on the *ongoing relationship with the deceased*, including allowing the deceased to have continued impact on life, keeping their memory alive or fears about harm to their body or their after-life (Walker et al., 2013). Factors related to the *family's future*, including hoping to increase togetherness and avoiding tension, are also considered, with family members influencing each other's decisions (Ralph et al., 2014). As staff get to know the family, they can help reduce conflict, contributing to respect for multiple views (Ralph et al., 2014).

### Provision of care in the hospital

Anker (2013) describes a family-centred approach where care and request outcomes co-evolve, family grief guides the process and the approach responds to family needs and readiness. De Groot et al. (2012) consider the desired outcomes of support, noting that most studies focus on support aimed at increasing consent rates rather than family satisfaction, stable evaluation of decisions, self-efficacy or empowerment.



**Figure 1.** Data selection – identifying and screening relevant reviews.

**Table 2.** Summary of the features of the selected reviews.

First author (year)	Aim (role players)	Search strategy described? (delimitations)	No. of studies	Method (PRISMA/AMSTAR)
Anker (2013)	Describe and compare approach strategies (organ procurement coordinators)	Not described (chapter in book – usual journal reporting format not followed)	15	Narrative synthesis (14/5)
De Groot et al. (2012)	Describe decision-making and decision evaluation (families of brain dead patients)	Yes; (English, Dutch and German studies published from January 1996 to February 2011)	70	Integrative review (22/9)
Falomir-Pichastor et al. (2013)	Identify determinants of donation (public and families of potential donors)	Yes; (English, French and Spanish languages)	131	Integrated framework (18/8)
Mills and Koulouglioti (2016)	Summarise evidence about nurses' support (nurses and family of potential organ donors)	Yes; (English language)	23	Qualitative coding (21/8)
Ralph et al. (2014)	Describe family perspectives on deceased donation (donor families)	Yes; (English studies published before October 2012)	34	Inductive thematic synthesis (24/10)
Simpkin et al. (2009)	Identify modifiable factors influencing decisions (family of potential organ donors)	Yes; (studies published before May 2008)	20	Thematic; narrative (23/11)
Walker et al. (2013)	Understand factors influencing decisions (families of potential organ donors)	Yes; (research from Western countries published between 2001 and 2011)	20	Integrative review; thematic analysis (24/9)

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses; AMSTAR: assessment of multiple systematic reviews.

**Table 3.** Summary of the main findings of reviews.

First author (year)	Main findings
Anker (2013)	A family-centred approach incorporating support and information fosters trust and assists families to decide. Trained requesters build positive relationships, balancing the needs of bereaved families and patients awaiting transplants.
De Groot et al. (2012)	Most studies focus on consent rates, rather than family satisfaction. Skilled requesters exploring family values and deceased's wishes contribute to stable decisions; respect is vital; providing choices fosters empowerment.
Falomir-Pichastor et al. (2013)	Explored how one's attitude towards donation develops, and the communication of donation preferences by family conversation or registration. This influences family decision-making after a death. Social inclusion, interaction, self-efficacy and emotion were identified as important factors.
Mills and Koulouglioti (2016)	Identified two themes: (1) clarity of communication and understanding and (2) nurse's competency. Support, understanding and care contribute to a supportive environment, enabling acceptance of death and consideration of donation.
Ralph et al. (2014)	Described emotional and cognitive struggle in an unfamiliar environment. Timely information and opportunities for participation improve satisfaction and assist families to find meaning.
Simpkin et al. (2009)	Requester skills, timing, information, high quality care of patient and family, understanding of brain death and a private setting are modifiable factors influencing family experience.
Walker et al. (2013)	Families focus on past (e.g. will of the deceased), present (e.g. comprehending the situation) and future (e.g. hopes and expectations) factors. Many consenting families find meaning in donation.

Pre-existing factors such as training, professional roles and team dynamics are relevant to the staff system. Staff can modify processes to improve the family's experience using '... adequate information ... high quality of care of potential organ donors ... and trained individuals to make the request' (Simpkin et al., 2009: 1).

### Co-creation of resources and risks

Factors mentioned above interact, contributing to emerging properties (Johnson, 2006) which can each be described on a resource-risk continuum. Five continua were identified: *understanding-confusion*, facilitated by the provision of information (Mills and Koulouglioti, 2016); *trust-doubt*, where staff should consider each family's unique characteristics (Anker, 2013) and provide access to support independent of the donation team (Ralph et al., 2014) or allow the family to appoint someone to act as the main link with hospital staff (Walker et al., 2013); *hope-despair*, where Walker et al. (2013) argued that understanding and acceptance of death enable consideration of future perspectives; *efficacy-helplessness*, where respect and meaningful choices contribute to self-confidence (De Groot et al., 2012); *closeness-distance*, where acknowledging family roles and activating family resources contribute to family involvement, and families should not be left feeling dismissed (Ralph et al., 2014). Depending on pre-existing factors, and in-hospital experiences, families will find themselves at different points on each of these resource-risk continua.

### Attending to tasks

Pre-existing factors and future-oriented considerations, in-hospital care and the co-creation of resources and risks

influence the family's ability to attend to the tasks of the in-hospital process. These tasks include initial or facilitative tasks such as *adapting* to an unfamiliar hospital environment (Mills and Koulouglioti, 2016) while coping with symptoms of *acute stress* such as shock and disbelief (Ralph et al., 2014). When staff appear to be unsupportive, emotional reactance (Anker, 2013) and post-traumatic stress (De Groot et al., 2012) may be experienced.

Family members will often need to *adapt to new roles and responsibilities* (Falomir-Pichastor et al., 2013). *Active participation* has been linked to satisfaction with the process (Walker et al., 2013) and family empowerment (De Groot et al., 2012). *Meaning-making* assists families to make sense of their experience and could include following their loved one's wishes, fulfilling a moral obligation or protecting their loved one's body (Ralph et al., 2014). Finding meaning can be complex, and relatives may be ambivalent about their values (protection and altruism) and the deceased's wishes (De Groot et al., 2012).

Developing resources and attending to the above-mentioned facilitative tasks provide a foundation, preparing families to attend to the main tasks of the in-hospital process. When family members realise that their loved one will not survive, they experience a brief period of *anticipatory mourning* where being involved, spending time with their loved one and 'saying goodbye' contribute to family satisfaction (Walker et al., 2013). Clear explanations of death assist the family to avoid false hope (Walker et al., 2013) and *accept death*, initiating *acute grief*.

The co-construction of the *post-death identity* of the deceased and the development of an *ongoing psychological bond* are important tasks. Attitudes of the potential donor and those of the family interact during decision-making (Falomir-Pichastor et al., 2013), highlighting the ongoing



relationship with the deceased. Grief could be adversely affected when relatives do not consider the deceased's preferences (De Groot et al., 2012).

*Decision-making* can contribute to confusion and disagreement, with about 10 per cent of donating families and up to 42 per cent of non-donating families later feeling uncertain about their choice (De Groot et al., 2012). Families view the potential for donation both as a *gift* and a *sacrifice*, and inability to tolerate this ambivalence has been linked to traumatic memories (Mills and Koulouglioti, 2016) and regret (De Groot et al., 2012).

Although it has been noted that qualitative research contributes to 'detailed *narrative* data to explain people's beliefs, attitudes and values' (Ralph et al., 2014: 932), the link between the *family narrative* and coping was not explored in any of the reviews. Mourning is a social process (Neimeyer et al., 2014), with family and staff participating together in creative narrative activities. The importance of the family narrative is therefore highlighted not by its inclusion in the identified reviews but by its absence.

### Connecting the categories

The Grounded Theory approach requires exploration of relationships between categories contributing to a theory that fits the data. For example, although resources, risks and tasks have been separated to assist with the introduction of new concepts, they are closely related. Completing tasks contributes to the building of resources which in turn makes the completion of tasks more likely. To describe further connections between categories, the additional concepts of *mechanisms* (Edling and Rydgren, 2016) and *outcomes* are introduced.

Mechanisms facilitate development of the emerging blend of resources and risks. Those associated with understanding-confusion, trust-doubt, hope-despair, efficacy-helplessness and closeness-distance are *information*, *sensitivity*, *co-creation of realistic goals*, *co-creation of meaningful choices* and *interaction*, respectively.

Family members are generally unprepared for the in-hospital environment (Ralph et al., 2014), and staff must deliver care that builds the family's capacity to overcome the initial impact of the unfamiliar context. This will contribute to *meaningful outcomes* when the co-created resources are used to attend to the in-hospital tasks. Similar to resources and risks, outcomes will later be described on continua.

## Discussion

In the previous section, findings of a systematic review of the literature were described. The relevance of those findings will be discussed in the context of the aims of the current review. First, implications for the understanding of family experiences will be discussed, and thereafter,

implications for the understanding of family bereavement will be explored.

### Understanding the family's in-hospital experiences

The categories described earlier can be seen as existing in a dynamic environment where interaction contributes to mutual influence. In order to attend to the first aim of the study, the features of this environment are explored in detail and incorporated into a comprehensive model.

*Theoretical perspectives.* At the time of a death, the family system experiences imbalances and individuals need to adjust to new roles (Mehta et al., 2009). The current model proposes that in the context where death contributes to the potential for organ donation, the family system and the staff system collaborate forming a *System of Systems* (SoS) (Haimes, 2012). Within the SoS, these two systems have their own internal structure and function separately when appropriate, while at other times functioning together.

The theoretical framework of SoS is useful in the present context and highlights both the independence of the staff and family systems and their dependence on each other when attending to tasks of the in-hospital environment. Key elements of this framework will be introduced next.

Haverkort (2013) describes an SoS as a complex system formed when two or more independent systems are integrated. As part of this definition, the independent systems retain operational independence (are able to function independently) and managerial independence (the structure and hierarchy of each system actually contribute to independent action).

The component systems have their own 'rules' and decision-making processes and they behave (at least in part) to attend to their own needs which are separate from the needs of the SoS as a whole, as well as attending to needs related to the SoS (Maier, 1998).

Haimes (2012) argues that the component systems may have different objectives and multiple decision-makers and stakeholders. For example, for the family, the injury and later, the death of their loved one is what brings them to the hospital, whereas the donation coordinator is there because a potential organ donor has been identified.

According to Maier (1998), the organising structure in a collaborative SoS is communication within and between the component systems. Therefore, understanding how communication can be facilitated and enhanced is directly related to the efficiency of the SoS. This links closely to the earlier reference to the use of information to facilitate understanding.

The characteristics of the SoS as a whole emerge as a function of the interconnectedness between the component systems rather than as a function of the component systems

**Table 4.** Multi-dimensional nature of the in-hospital process.

Features	Cognition	Emotion	Future orientation	Behaviour	Relationships
Resources and risks	Understanding vs confusion	Trust vs doubt	Hope vs despair	Efficacy vs helplessness	Closeness vs distance
Mechanism	Information	Sensitivity	New goals	Choices	Interaction
Delivery of care	Consistency; clarity	Patient and family care	Facilitate shift of hope focus	Acknowledge family roles	Encourage participation
Influencing factors	Pre-existing beliefs	Trust in system	Independent counsellor	Family resources	Available time
Factor modified	Information in various forms	Meet needs efficiently	Develop view of future	Adjust tasks to fit family	Family involvement

The factors described above are not intended to be exhaustive but rather to illustrate themes identified by the review process. Each family's experience is different and complex.

themselves (Johnson, 2006). In the current SoS, the resources and risks are seen as important characteristics which emerge as a result of the interaction between family and staff.

According to Haimes (2012), models of systems attempt to represent the characteristics of the SoS in a way that contributes to clearer understanding of how component systems interact with each other and internally how the members of each system interact with each other. A model should contribute to insights which enhance understanding and facilitate improvement.

Haimes (2012) suggests that an improved understanding is reached when the SoS is broken down into its component systems and subsystems. Haimes (2012) describes modelling as an interplay between theory and prior knowledge about the SoS on one hand, and a learn-as-you-go inquisitive and exploratory process on the other hand. As such, it is both a science and an art. Models must be as simple as possible, but as complex as required, taking human cognition, perception and behaviour into account (Haimes, 2012).

When creating a model of an SoS, Haimes (2012) emphasises the value of having multiple views of the system, each highlighting certain aspects of the whole. When the multiple views are incorporated, they are seen to increase the effectiveness of the resultant models. This was achieved in this study using seven systematic reviews investigating varying aspects of the in-hospital process, compiled by researchers from different disciplines.

**Details of model components.** Table 4 shows the emergence of resources and risks which describe dimensions of cognition, emotion, future orientation, behaviour and relationships. For example, information (mechanism) can be presented in different forms (modifiable factors) while being consistent (delivery of care). This information interacts with the family's pre-existing beliefs (influencing factor) contributing to a blend of confusion (risk) and understanding (resource).

Tables 5 and 6 describe engagement in tasks. For example, to assist with meaning-making (task), staff can create

opportunities to share stories (delivery of care) and assist family members make sense and understand significance (modifiable factors) so that they can adjust their global meaning (influencing factor). This contributes to a blend of meaning being made and cognitive dissonance (outcomes which are described on a continuum rather than being binary). The remaining columns of the tables can be understood in the same way.

The tasks of co-creating the identity of the deceased, developing an ongoing bond and developing the family narrative are important parts of the model. Staff members initially identify the patient as a potential donor, while for the family, he or she is a loved one. By listening to the family's stories, staff members get to know the patient as a person, and after understanding explanations given by staff, family members consider the possibility of their loved one becoming an organ donor, and the family becoming a *donor family*.

Figure 2 shows the features of the in-hospital process that have been discussed, including the staff and family component systems interlocking to form the SoS. Each of the component systems is shown as having pre-existing factors that are relevant, and the resources, risks and tasks are shown inside the SoS because they are shaped through the interaction between family and staff. Although the pre-existing factors, tasks, resources and risks are located separately in the diagram for clarity, it is understood that in the complex SoS, all elements are continually interacting and contributing to the process and its outcomes.

A model is a simplified representation of a process, and in the in-hospital context, factors will have influence across columns and tables, contributing to complexity. In order to demonstrate this complexity, information from Tables 4, 5 and 6 was used to create a comprehensive graphical representation of the SoS. In producing this systemic map, the theoretical and practical framework of *Systems Practice* was used.

According to the Omidyar Group (n.d.), Systems Practice is ideal when working in contexts characterised by complex social phenomena. The Omidyar Group (n.d.)

**Table 5.** Facilitative tasks of the in-hospital process.

Features	Adapt to environment	Acute stress	Roles and responsibilities	Active participation	Meaning-making	Anticipatory grief
Delivery of care	Staff support and guide	Normalise symptoms	Adjusting of tasks	Providing choices	Opportunities to share stories	Encourage family involvement
Influenced by	Past experiences	Traumatic event	Role of deceased	Medical trust	Global meaning	Hospital stay
Factor modified	Understanding environment	Understanding of acute stress	Family members take on new tasks	Level of family activity	Sense and significance	Meaningful 'goodbye'
Outcomes	Endurance vs exhaustion	Change symptom tolerance	Self-confidence vs self-doubt	Sense of agency vs anxiety	Meaning made vs dissonance	Purpose vs unclear direction

**Table 6.** Main tasks of the in-hospital process.

Features	Accepting death	Acute grief	Post-death identity	Post-death bond	Decision-making	Family narrative
Delivery of care	Provide time of death	Care; understanding	Encourage sharing of memories	Facilitate family time with deceased	Clarity; adjust timing; setting	Opportunities to share stories
Influenced by	Hope for recovery	Family roles; prior losses	Openness in family	Nature of pre-death attachment	Family values; knowledge	Existing narrative and meanings
Factor modified	Family understanding	Family feel supported	Rich descriptions of deceased	Psychological connection	Family informed and ready	Finding links and patterns
Outcomes	Acceptance vs denial	Managing pain of grief vs avoidance	Shared view of identity vs diffusion	Secure vs anxious attachment	Satisfied with stable decision vs uncertainty	Co-created narrative vs lack of coherence

describes a rigorous approach to grappling with the understanding of complex environments with the aim of identifying opportunities for enduring change. This approach was used, with seven systematic reviews acting as the data source, to gain an understanding of the in-hospital environment as a complex, dynamic system.

Systems analysis contributes to a map providing a detailed visualisation of the context being explored. Displaying the information in this way contributes to new insights and depth in the understanding of the system. The Kumu Systems Mapping Tool (<https://kumu.io>) was found to be an ideal way to produce the actual map while following guidelines described by the Omidyar Group (n.d.).

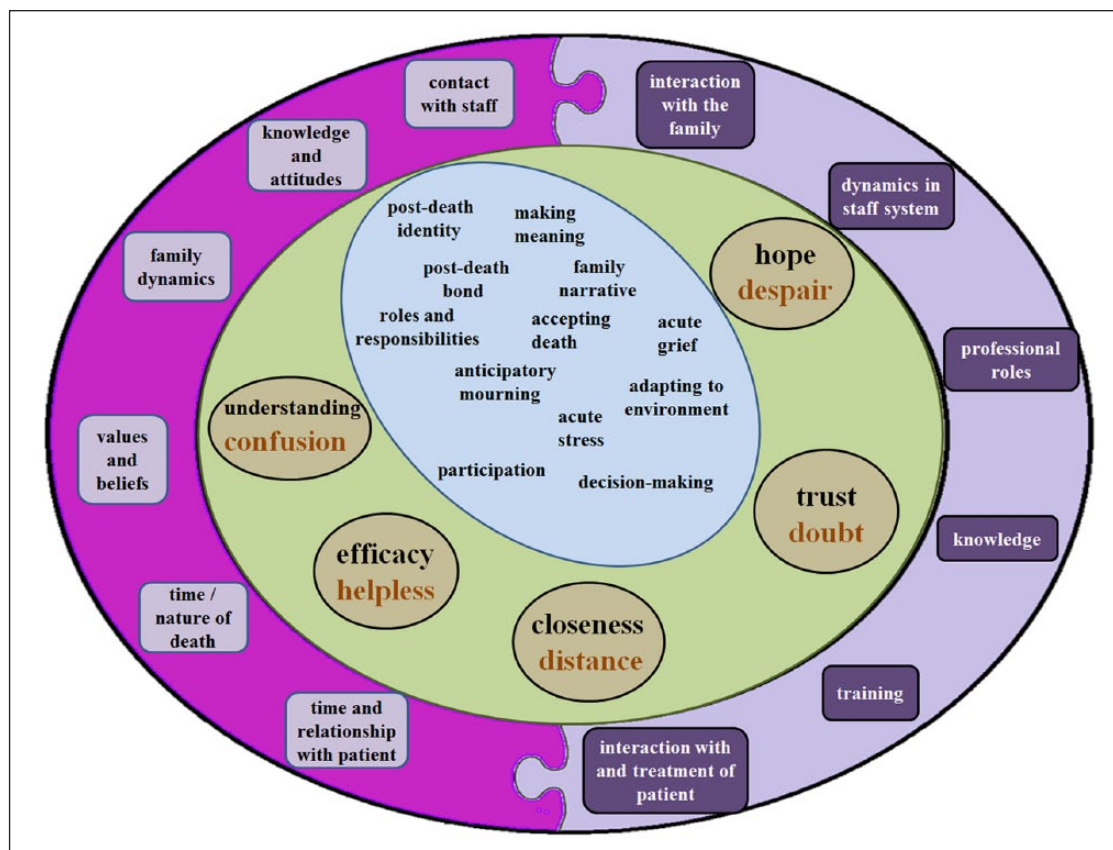
Initially, the information from the tables was used to construct 18 loop diagrams – one for each resource-risk continuum and one for each task. The loops were printed and cut out separately. Using methods described by the Omidyar Group (n.d.), these loops were moved around on a table, while similarities and differences between them were considered. Loops with similar elements were clustered together and shifted around iteratively in order to use them to describe the behaviour of the system. When the picture made sense, the deep structure of the system emerged as zones which held the loops together (The Omidyar Group, n.d.: 41).

A systemic map is never 'correct' because logical connections could have been made in different ways contributing to different zones, or different labels could have been chosen for zones. The question to be asked should therefore

not be 'Is this the real map?' but rather 'Is this a useful map in that it facilitates understanding and action?' or 'Does the map reflect the data on which it is grounded?' We believe that the answer to each of the last two questions is 'Yes'. The identified elements and the connections shown between them are directly related to the reviews. The naming of the emergent zones also reflects terminology used in the reviews.

**Properties of the SoS emerging from the model.** The model suggests that the primary resource-risk continua and tasks described earlier contribute to the emergence of secondary continua and tasks in the context of interaction between the family and staff component systems. To simplify textual discussion, each continuum will be described below in terms of the appropriate resource alone.

With reference to Figure 3, Understanding, supported by *scaffolding* and *making information useful*, has the potential to contribute to *shared ownership* and also influences *coming to terms with death*; trust plays a role in the development of *social inclusion* and influences the tasks of *family-centred care*, *considering organ donation* and *confronting the moral dilemmas*; hope influences *feeling connected*, coming to terms with death and *adjusting global meaning*; efficacy is shown as being related to *collaboration*, *shared ownership*, *supportive environment* and *family empowerment*; closeness influences the emergence of family empowerment, supportive environment, family-centred care and social inclusion.



**Figure 2.** Diagram showing family and staff systems, pre-existing factors and in-hospital resources, risks and tasks.

The emergence of *perseverance-withdrawal* in the centre of the map is particularly significant. It suggests that secondary continua and tasks contribute to family perseverance. (The extent to which this may contribute to resilience and later to post-traumatic growth will be explored in a longitudinal study.) This growing perseverance would in turn assist the family to develop the resources mentioned while attending to tasks. This could be seen to contribute to the family's *Capacity for Action* versus *Feeling Overwhelmed*, which seems to be a useful way to look at the left side of the map (see Figure 4) where family members are supported in preparation for their active participation described on the right side of the map.

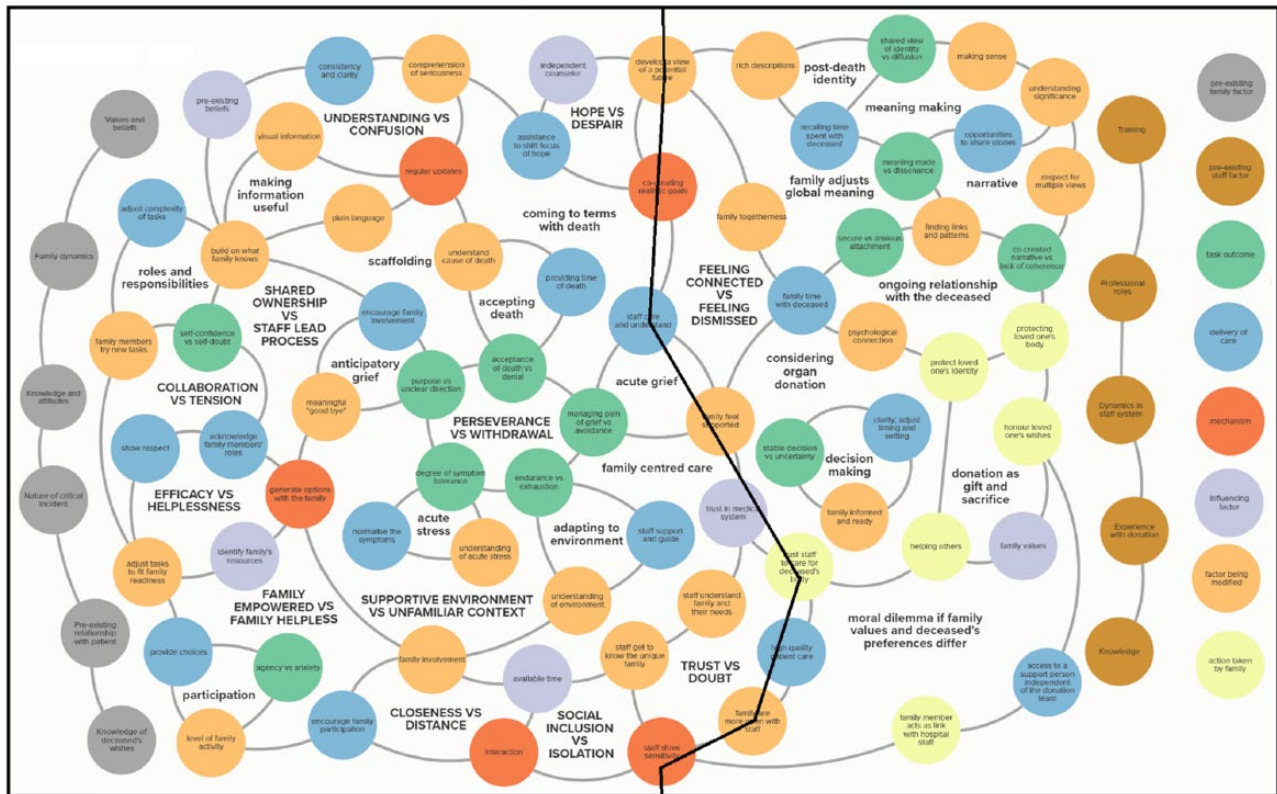
It seems appropriate to suggest that a regulatory relationship may exist between shared ownership, perseverance-withdrawal and family-centred care. In this relationship, when family members show greater perseverance, staff could give more control to the family, whereas when the family shows signs of stress and the risk of withdrawal, more support and care would be appropriate. In other words, by monitoring perseverance, staff could determine whether more support was appropriate or whether family members are ready to take more responsibility. This is important because family should 'arrive' on the right side of the map feeling capable rather than overwhelmed.

On the right side of the map, there is an increased level of family-driven activity indicating that a shift occurs. It tells the story of the family's attempts to make sense and create meaning that will ultimately shape their decision about donation and have implications for their ongoing bereavement. The perseverance that was built earlier plays a vital role as the family confronts new tasks (such as *adjusting global meaning*), new ambiguities (e.g. looking at *donation as simultaneously being a sacrifice and a gift*) and dilemmas (e.g. trying to balance the deceased's preferences (known or implied based on characteristics), family values and the family's in-hospital experience).

While there are opportunities for staff to provide support, suggested by the placement of family-centred care (and also the staff-related factors on the right border of the map), the course of events on this side of the map depends strongly on family actions, dynamics and choices. The right side of the map has been conceptualised as a task and has been named *search for closure*. The outcomes of this task would relate partly to making a decision about donation (where a confident, stable decision may be made or ongoing anxiety and uncertainty may be felt). However, the search for closure is also related to the family's meaning-making efforts (described in the top right of the map), and in that regard, the outcomes of co-constructing a coherent







**Figure 4.** The diagram shows the in-hospital process as being related to developing capacity for action (on the left), which is vital later when searching for closure (on the right).

than described by previous stage-oriented models. According to Worden's (2009) model, the bereaved attend to the tasks of accepting the reality of the loss, working through the pain of grief, adjusting to an environment in which the deceased is missing and developing an enduring connection with the deceased while embarking on a new life. Bereavement is not expected to follow these tasks in a linear way. Instead, the bereaved move back and forth between the tasks during their bereavement.

Also relevant to this study is Neimeyer et al.'s (2014) description of grieving that includes finding meaning in the death, reconstructing a self-narrative perturbed by loss, negotiating the shared transition with others in the family and renegotiating a continuing bond with the deceased in emotional, symbolic and memorial terms.

Looking at the map through the lens of grief theory, the cluster around perseverance-withdrawal tells the story of the family's initial experiences of their loved one's death and their engagement in the process around the death. While opportunities to be actively involved in the hospital process could potentially assist in the development of family empowerment and shared ownership in relation to the unfolding process, the family cannot change the fact that their loved one has died or will die.

In this context, they must accept the death and experience the pain of the loss, the first two of Worden's (2009)

tasks of grief. This initial experience could also be seen to show the *loss-orientation* described in Stroebe and Schut's (1999) DPM.

On the right side of the map, the family is required to adjust to the implications of the death and demands of the hospital setting in order to make a decision on behalf of the deceased. This process involves more activity on the family's part, and can be seen to touch on Worden's (2009) third and fourth tasks of adjusting to an environment where the deceased is missing, and finding an enduring connection with the deceased. This side can also be seen to relate to Stroebe and Schut's (1999) second process of *restoration* which involves the bereaved focusing on tasks and responsibilities that follow the death of a loved one. The right side of the map also highlights meaning-making, social interaction and rebuilding the family narrative. These activities are associated with the narrative and social constructionist theories of grief and mourning (Neimeyer et al., 2006, 2009, 2014).

The map confirms Sque et al.'s (2003) assertion that grief begins at the hospital, and bereavement care should begin there too. Relationships between components demonstrate opportunities for staff to contribute to the family's bereavement experience both in terms of loss-orientation and restoration-orientation.

The graphical representation of the model (Figures 2 and 3) centralises resources, risks and tasks, while the family

and staff systems (and their pre-existing factors) are shown as equal component systems of the SoS, graphically depicted on the sides contributing to the shape of the SoS. Because they know the process and family members do not, staff members have responsibilities related to facilitating the family's understanding, adaptation, engagement in resource-building and attendance of tasks, while learning from the family, and shaping the environment to meet family needs.

The model prioritises service delivery and demonstrates how the identified social resources can act as leverage contributing meaningfully to the family's bereavement. In particular, the model highlights the potential leverage that would be obtained by efforts to build on family perseverance and facilitate the family's adjusting of their global meaning. The significance of psycho-social factors is demonstrated by this model and supports suggestions that providing a neutral support person would assist the family to navigate this complex process (De Groot et al., 2012; Ralph et al., 2014) and allow medical staff to avoid dual roles.

### Relevance of the proposed model

Over the last 25 years, a number of models have developed linking aspects of the in-hospital process at the time of a potential organ donation. For example, Sque et al. (2003) demonstrated the need to creatively approach the provision of information to families and suggested that information is best delivered in complementary ways. Sque et al. (2003) further highlighted the need to show care that fits the family's needs and the need to give attention to the unique family when considering the timing of information provided and the family's capacity to process that information. Falomir-Pichastor et al. (2013) and Ralph et al. (2014) each constructed a model and, following their reviews, De Groot (2016) and Walker and Sque (2016) did so too. These models demonstrate connections and relationships between role players and concepts.

The currently proposed model does not challenge existing models, but complements and expands on them. Previous models explore family experiences mainly in relation to the decision-making task, while the present model has a broader focus. At the same time, depth provides insight into the building blocks that contribute to concepts used in the other models. Ways of describing the unfolding processes, and identifying points of early intervention, are demonstrated in the systemic diagram. The systemic perspective and the SoS model highlight the role of family members as co-creators of the in-hospital experience acting alongside staff with both component systems contributing to the eventual outcomes of the process.

### Implications for research

The review highlighted gaps in the literature, including the need to consolidate knowledge of grief-related experiences of families of potential organ donors, and includes grief theory to assist our understanding. In addition, there is a

need for differentiation between the experiences of families participating in decisions following brain death and those where donation is possible after circulatory death, as well as increased inclusion of the perspectives of families who declined donation and those where donation could not proceed after they had consented (De Groot et al., 2012; Ralph et al., 2014; Walker et al., 2013).

### Limitations

Only English reviews were identified and they each described their own limitations which were 'inherited' by the current review. The stated aim of this review was to understand family experiences, and this is reflected in the search strategy. The idea of an SoS developed over the course of analysis and the model propose that family and staff are equal role players during the in-hospital process. The systemic framework would imply that there is mutual influence during interaction. However, the literature search was not designed to identify studies demonstrating the impact of the process on staff. In order to fully explore the implications of using the SoS model, a review of the impact of the process on staff is required.

Since the publication of included reviews, other studies have explored aspects of the family experience. Findings of those studies are congruent with ideas presented and will be incorporated when the model is tested by means of a longitudinal study to explore its fit with family experiences. In order to explore the usefulness of the model, it is also necessary to determine whether viewing the process in this way assists staff to identify opportunities to improve family care.

### Strengths

Improved care facilitates family well-being (Anker, 2013). This review contributes by drawing on diverse insights of seven review teams. The conceptualisation of the SoS and the inclusion of systemic properties bring into focus complexities that have previously made understanding the process difficult. However, the model's focus on interaction provides a foundation for the description, evaluation and improvement in services provided to families of potential organ donors during the in-hospital process.

### Conclusion

The proposed model demonstrates that there is more to the in-hospital experience than decision-making. A number of tasks are described, and it is suggested that staff and family together shape the social resources required to address those tasks. Relating the family's in-hospital experience to the theories of Stroebe and Schut (1999, 2015), Worden (2009) and Neimeyer et al. (2006, 2009, 2014) demonstrate the links between this process and family bereavement, identifying opportunities for enhanced care.



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