Grief, Stress, Trauma, and Support During the Organ Donation Process

Sean G. Dicks, MA, Nadia Burkolter, MNursing, Lyndall C. Jackson, GradCertMNursing and GradCertNursing Nursing, Holly L. Northam, PhD, Douglas P. Boer, PhD, and Frank M.P. van Haren, PhD

Abstract. The organ donation process is complex and stressful for the family of the potential donor and members of the multidisciplinary team who may experience grief, ethical dilemmas, vicarious trauma, or compassion fatigue. Several studies each explore the role of a specific healthcare group and the impact of inhospital processes on group members. We conducted a systematic literature search to identify such studies and a qualitative synthesis to consolidate findings and highlight features of the interaction and relationships between role players. Our results suggest that, while healthcare professionals have different roles, attitudes, and views, the experience of stressors and interdisciplinary tension is common. Nevertheless, staff are united by the goal of caring for the patient and family. We therefore propose that, while focusing on bereavement care and other aspects of the family’s experience, staff can find other shared goals and develop understanding, trust, empathy, and respect for each other’s positions, thereby improving functioning in the complex adaptive system that forms at this time. Education and training can equip staff to facilitate anticipatory mourning, family-led activities, and a meaningful parting from their relative, assisting families with their grief and increasing staff members’ efficacy, confidence, and interdisciplinary teamwork. Knowledge of systems thinking and opportunities to share ideas and experiences will enable staff to appreciate each other’s roles, while supportive mentors, self-care strategies, and meaningful feedback between role players will foster healthy adjustment and shared learning. A focus on psychosocial outcomes such as family satisfaction with the process, collaboration within the multidisciplinary team, and reduction in the role stress of healthcare professionals will contribute to family well-being as well as personal and professional growth for staff.

Received 30 April 2019. Revision received 21 October 2019.
Accepted 22 October 2019.
1 Faculty of Health, University of Canberra, Canberra, ACT, Australia.
2 Canberra Health Services, Canberra, ACT, Australia.
3 School of Medicine, Australian National University, Canberra, ACT, Australia.
The authors declare no conflicts of interest.
All the authors made significant contributions to the manuscript. S.G.D. developed the original plan and applied for a Research Support Grant. S.G.D. and N.B. contributed to further development of the plan and identification of literature search criteria. S.G.D. conducted the electronic search, and S.G.D., N.B., and L.C.J. screened sources and reviewed reference sections and citation histories to identify further sources. S.G.D. iteratively drafted and redrafted the manuscript in response to input from all other authors and later in response to comments made by anonymous reviewers. PhD supervisors (H.L.N., D.P.B., and F.M.P.V.) provided input and guidance throughout the abovementioned process. S.G.D., N.B., and L.C.J. acknowledge the receipt of an Allied Health Research Support Grant from the Australian Capital Territory Health Directorate (ACT Health), Australian Capital Territory (ACT). S.G.D. acknowledges that, as a PhD candidate, support was received through an Australian Government Research Training Program Scholarship.
Supplemental digital content (SDC) is available for this article. Direct URL citations appear in the printed text, and links to the digital files are provided in the HTML text of this article on the journal’s Web site (www.transplantationdirect.com).
Correspondence: Sean G. Dicks, PhD Candidate, Department of Psychology, University of Canberra, GPO Box 2148, Canberra, ACT 2601, Australia. (sean.dicks@canberra.edu.au).
Copyright © 2019 The Author(s). Transplantation Direct. Published by Wolters Kluwer Health, Inc. This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.
ISSN: 2373-8731
DOI: 10.1097/TXD.0000000000000957

Participation in the ad hoc system forming when a potential organ donor is identified is stressful for families facing an unexpected death in an unfamiliar environment and for healthcare professionals (HCPs) who provide medical care, information, and emotional support. Before considering organ donation, family members must accept that their relative is brain dead, making donation possible via the donation after brain death pathway, or that further medical treatment would be futile in the case of the potential to donate organs after withdrawal of cardiorespiratory support and circulatory death (the donation after circulatory death [DCD] pathway). Consenting families must also accept that medical and logistical factors may nevertheless prevent organ donation.

Inhospital events influence HCPs regardless of the donation decision. Family and staff well-being must therefore be monitored, and practices that are theoretically grounded and empirically validated should be implemented to assist family members and HCPs. However, although much research explores the donation pathway, rigorous evaluation of the impact of their participation in the ad hoc system on family well-being as well as personal and professional growth for staff.
request process, 29-32 bereavement care has received less attention. 21,33,34 Consequently, while expressing confidence in task-oriented aspects of this context, staff often report uncertainty when providing emotional support 25,35 or managing their own grief. 10,36,37

Factors influencing inpatient outcomes include staff knowledge and attitudes, 38 suggesting that the content of university courses is important; 39-40 policies and procedures, suggesting that policy makers play a role; 38-40 and medical aspects of the particular admission. 41 We will not explore these factors in detail but rather focus on psychosocial experiences of HCPs involved during the inpatient process. The terms HCPs or staff will be used when content refers to several roles, and specific roles will be named when this is appropriate. According to a complex adaptive system (CAS) framework, dynamic systems cannot be understood by exploring individual roles alone. Therefore, we assume that links and interaction between role players influence emerging properties and outcomes. 42-47

**AIM**

We aim to foster empathy and understanding of the impact that processes have on HCPs playing different roles in the CAS. We will also demonstrate that it is useful to view this context through the lenses of grief and systems theory, and we suggest leverage points that could enhance staff well-being and system functioning. We hope to encourage those working in this field to reflect on the impact that the context has on them and the impact of their actions on the experiences of others.

**Box 1: Summary of our method and findings**

Rather than selecting studies adhering to strict predetermined criteria and then evaluating the methods, analysis, and findings, we selected diverse sources focused on the experiences of various HCPs at the time of the potential for organ donation. Data from these sources were blended to create an informative narrative to provide readers with empathic understanding of challenges faced in this context. Thematic analysis identified 6 themes and highlighted 3 leverage points, which can assist role players to optimize functioning and coping in the ad hoc system that forms when a potential organ donor is identified.

**MATERIALS AND METHODS**

A systematic literature search identified sources describing the participation of several role players in the organ donation context. Sources describing HCP experiences of inpatient stress, grief, family care, and staff care were selected, while those focusing on raising awareness of technical or medical aspects were excluded. Our synthesis differs from an *standard* systematic review in that it aims to contribute to empathetic understanding of the system rather than a critical appraisal of studies or consolidation of what is known about presuppecified variables.

Projects such as the Organ Donation Collaborative in the United States of America, 46 the Organ Donation Taskforce in the United Kingdom, 29 and the Organ and Tissue Donation Authority in Australia currently shape the international organ donation context. We therefore sought sources published between 2010 and 2018 to capture present understanding and practice. However, while several sources published during this period explore experiences of medical and nursing staff, fewer were found addressing participation of nonmedical staff. Therefore, sources addressing experiences of allied HCPs were included if published between 2000 and 2018.

An electronic search identified 662 sources, and 53 that were known to authors were added. After removing duplicates and screening titles, abstracts, and full-text copies, 63 sources remained. Another 15 were identified by searching reference sections and citation histories. While drafting the manuscript, search alerts were left active, contributing to the identification of 6 new articles and a total of 84 sources (see Figure S1, SDC, http://links.lww.com/TXD/A229). These include original research articles, book chapters, systematic reviews, case studies, PhD theses, best practice guidelines, and editorial comments (see Table S1, SDC, http://links.lww.com/TXD/A230).

We used the criteria of credibility, dependability, and transferability to evaluate our manuscript. 51 The literature search identified a rich dataset consisting of multiple, relevant peer-reviewed sources that met inclusion criteria. We then developed a credible narrative that reflects the findings of those sources. This narrative and our later discussion can be traced to the selected sources using the citations provided, thereby demonstrating dependability. Dialogue within the multidisciplinary authorship team ensured congruence between this narrative, current practice and HCP experiences, thereby increasing transferability. The narrative style of the “RESULTS” section enables readers to become familiar with the literature without our interpretations so that they may judge the appropriateness of our synthesis and recommendations that are presented in the “DISCUSSION” section.

**RESULTS**

After highlighting the relevance of preexisting psychosocial factors, HCPs’ experiences are explored by following the possible journey of the potential donor and their family through the hospital. We include descriptions of the emergency department (ED), intensive care unit (ICU), and operating theater (OT) and introduce the donation coordinator and support coordinator (who participate across settings) and visiting transplant surgeons at appropriate places. Stressors and opportunities are introduced at logical points without implying that some HCP groups experience these features, while others do not.

**Box 2: Interaction contributes to the psychosocial context**

We have included reference to the identification and response to family needs throughout the article, because family reactions and coping styles contribute to the psychosocial context and because assisting the family is consistently described as being important to staff meaning making. Likewise, relationships between different staff groups are described, because these are also significant features of the inpatient environment.
**Preexisting Psychosocial Factors**

The event causing death, the deceased’s role in the family, family dynamics, culture, and other factors influence HCPs’ experiences and grief. Mental associations between HCPs’ personal narrative and characteristics of the patient are important, and preexisting capacity to provide and receive support is also relevant.

**The ED**

In emergencies, families hope that arrival at an ED will enable life-saving treatment. However, ED physicians will need to inform family members of potential organ donors that their relative will not survive. Physicians may experience an ethical dilemma when they are expected to then refer the family to an organ donation agency. Several physicians feel that this creates a dual role, conflicts with their duty of care, and reflects their failure to save the patient. In addition, they acknowledge that there is little time for physicians to explore organ donation with families.

To resolve these dilemmas, some adopt a neutral position when mentioning organ donation. However, this may contribute to lack of understanding which could harm trust, especially if family members develop a false impression regarding the patient’s prognosis and the family’s options. Lack of clarity has also been associated with family ambivalence, regret, intrusive thoughts, depression, complications in bereavement, and posttraumatic stress disorder.

Some physicians are unwilling to transfer a potential donor to ICU, except after consent for donation has been obtained, while others feel that the patient should be declared brain dead before a referral is made to an organ donation agency. These views hinder the opportunity for coordinators to develop relationships with family members and exclude the referral of potential DCD donors. Although some physicians argue that ethical dilemmas are reduced when families raise organ donation themselves, researchers warn that families acting based on their relative’s preferences or family members’ pronouncements of organ donation views alone may underestimate the complexity of the processes.

Although the situation is complicated, little attention has been given to these challenges. Given that physicians cannot know the most suitable way forward on their own, they should assist families to make informed decisions about their relative’s death. It has been argued that clear descriptions of treatment provided, the patient’s prognosis, and the family’s options, delivered by the treating physician and an organ donation specialist, are appropriate. Explanations provided should balance availability of information and the family’s ability to comprehend that information. Because sharing bad news at this time is delicate, training is necessary to assist HCPs to respond to the family and manage their own stress. Knowledge of crisis intervention techniques would assist HCPs to support family members and colleagues in ways that foster creativity and resilience.

Although HCPs identify several ethical issues in this context, families often focus on other matters. Many report that clarity and respectful communication is appreciated, and they therefore feel that someone able to answer questions about processes and options should be present when organ donation is first raised. Being present would also be useful to coordinators, because they would know what information was shared with the family, enabling repetition where necessary.

Family and staff require a palliative care approach that includes addressing their grief. HCPs must make sense of what happened, understand its significance, and find meaning. However, with little time to consider options when efforts to save the patient’s life were not successful, they may struggle to shift their attention to another goal. This may explain why, although most physicians express general support for organ donation, some are hesitant to refer a potential organ donor.

**Family Stressors and Opportunities**

Consideration of organ donation contributes to stress especially when family members struggle to comprehend aspects such as brain death or futility of treatment or when they do not know their relative’s preferences. However, because understanding these concepts is critical to their acceptance of their relative’s death and their later bereavement, whether they consider organ donation or not, families must be assisted to tolerate this stress while preparing to make informed decisions. Research suggests that in a family-centered environment, consideration of organ donation does not negatively impact grief.

Through conversation, families construct the postdeath identity and biography of their relative and contribute to a psychological bond and family narrative. However, many families are spread out geographically and unable to grieve together after leaving the hospital. It is therefore vital to use available opportunities for togetherness at the hospital to foster personal growth and appreciation of life. HCPs report that assisting families at this time is emotionally and professionally satisfying regardless of the pathway or donation decision or whether medical and logistical factors allow donation. Families report that support contributes to increased hope and resilience.

**HCP Stressors and Opportunities**

HCP grief challenges personal and professional roles contributing to uncertainty and evoking tension between concern for the patient’s family and the expectation of professional detachment. In response, some HCPs may adopt ineffective coping mechanisms including excessive avoidance of grief while others may find a constructive balance between sharing grief with colleagues and managing grief on their own.

In a complex environment, role players each have a limited view of unfolding events. These mean that individual HCPs cannot observe the family’s journey in totality and may consequently aim to protect the family from further complexity and themselves from dilemmas such as those described earlier. However, with a holistic understanding and information from trusted sources, HCPs can make a referral for consideration of organ donation knowing that their patient and his/her family will be cared for.

For example, referring to a letter received from parents of a young organ donor, a physician describes the value of family feedback:
I found myself crying, and still do when I think about that letter. It was honest. It is what we all need. Reaching out to each other to share the joys and the desairs of life. It is the answer to my questions.109

It is vital that HCPs receive support110,111 and maintain their mental health, because repeatedly exposed to traumatic circumstances and death can contribute to compassion fatigue (CF)112,113 and vicarious trauma (VT).114,115 Symptoms associated with CF include exhaustion and decreased compassion,112 while VT involves physical, affective, and cognitive symptoms,115 including nausea, tiredness, insomnia, helplessness, frustration, powerlessness, despair, and the loss of a positive outlook.114 On the other hand, with appropriate support and a positive team culture,116 HCPs can experience vicarious posttraumatic growth characterized by appreciation of life, clear perspectives, being more accepting of others, self-awareness, and empowerment.114

The Donation Coordinator

Donation coordinators must be able to make connections,117 show cognitive flexibility, and read nonverbal cues.118 The requester’s communication style29-31 contributes to the family’s experience119 with an empathic, family-centered approach balancing bereavement care and assisting families to make informed decisions.29

Although links between the donation coordinator and treating team are vital and can contribute to positive relationships and shared responses to challenges,65,120 HCPs have expressed concern that donation coordinators are not always transparent.109 This perception relates to referrals and assessment of the potential donor’s suitability being made without family knowledge and to coordinators introducing themselves without disclosing their role.108 Coordinators experience a dilemma in that, to obtain consent to assess suitability for donation, detailed conversations with families would be required, while without some information, it would be unclear whether the discussion with the family was appropriate.117,118

The Support Coordinator(s)

HCPs have reported that when their duty of care to the patient and the family seems to contradict hospital or national policies that prioritize identification and referral of potential organ donors, role conflict is experienced.26,121 On the other hand, when referring a family to an organ donation agency, simultaneous referral to a support coordinator can reduce this conflict.122 A palliative care team,123 pastoral carer,6,122 or social worker122 with expertise in crisis management, grief counseling, and resource mobilization could perform this role.

Support coordinators can monitor dynamics within and between the family and staff systems and ensure that staff identify and respond to family needs.120-127 Collaboration with a family member or family friend who is less traumatized by the event,18 and therefore able to clarify matters for other family members, can contribute to shared ownership of the process.128 At the same time, linking with key staff members could ensure that staff support needs are met.57,129

To prepare for their roles, support coordinators should learn about the organ donation context and medical aspects of donation after brain death and DCD,121 possibly by means of a simulation.130,131

The ICU

To family members and HCPs in the ICU, mechanical ventilation creates the appearance that the patient is merely sleeping. This could contribute to ambiguous loss, where the dying or deceased person seems present but has lost the persona they once had.132 ICU nurses report that caring for a potential organ donor and family members is challenging but also meaningful.27,57,99,121,133 Because HCPs’ perceptions and attitudes regarding organ donation influence their decisions and behavior,100 staff should analyze their feelings and values before advising or advocating for families134,135 to ensure that decisions reflect family priorities.1,58,100

When donation has been declined, HCPs can find meaning by assisting the family to create a respectful environment during withdrawal of cardiorespiratory support,29 while when families consent to donation, it is also vital that HCPs continue to provide support. However, in this busy environment, families have noticed that when ICU staff are overloaded with responsibilities, care of the patient and addressing of the family’s practical needs take priority, leaving little time for attention to emotional needs.139

Some consenting families prefer to part from their relative before surgery, while others appreciate assistance to create a meaningful farewell after surgery. This highlights the importance of awareness and respect for family needs and preferences.1,142 HCPs should also be encouraged to say their goodbyes to the patient and their family,17 acknowledging the emergence of shared experiences and hopes in this context.91

The OT

Assisting during organ retrieval surgery can be difficult for OT nurses.141 Many feel unprepared and overwhelmed but hide these feelings and receive little support,10,24 while some report disappointment when they are not given the option of declining participation.142 Some OT staff find that meaning based on honoring the preferences of the donor and respecting the family’s decision help reduce personal concerns.5,143

Many HCPs feel that they cannot express their grief because of the need to maintain professional boundaries, contributing to disenfranchised grief that is not acknowledged or socially supported.36 In response to concerns that ways of showing respect to organ donors and their families were lacking in the OT, a center introduced a practice where a short family-designed statement was read aloud and followed by a 15-second silence before surgery.144 This intervention assisted OT staff and families to make sense of the context while establishing positive links between families, ICU, and OT.144,145

Transplant Surgeons

Transplant surgeons work long, irregular hours, traveling to various hospitals and interacting with unfamiliar OT teams. Compared to other surgeons, they report the highest rates of depression, the most nights on call, and the most hours worked per week (average 69.5 hours).146 These demands can contribute to burnout, emotional exhaustion, and interpersonal stress, leading to surgeons distancing themselves from others.146 This correlates with OT nurses’ descriptions of visiting surgical teams as disconnected and unsupportive.5,10,28 During donation surgery, surgeons and OT nurses tend to get on with their roles with little interaction or support except when directly related to their respective tasks. Nevertheless, despite stressors experienced, transplant surgeons report high levels of professional satisfaction and active participation in their work.146,147
DISCUSSION

Themes extracted from the results section include (1) misunderstanding and the emergence of distrust; (2) multiple settings and the emergence of blind spots; (3) stressors and the emergence of physical, affective, and cognitive symptoms; (4) disenfranchised grief, excessive avoidance of reactions to the patient's death and the lack of avenues for staff support; and (5) excessive task-oriented interaction and the emergence of relationships that lack depth and empathy.

The potential for misunderstanding and distrust is shown when policies are seen to value organ donation rather than patient care; when ED physicians are seen to hinder the potential for organ donation by being hesitant to make referrals; when donation coordinators are seen to lack transparency, because they do not fully disclose their role when introducing themselves; and when transplant surgeons are seen to lack empathy when they quickly perform surgery and leave.

The multiple settings involved in the organ donation process contribute to blind spots, where role players are unable to see beyond given horizons to grasp the complexities and opportunities inherent in the process as a whole.

We have described some of the stressors encountered in this context, including ethical dilemmas, perceived conflicts of interest, ambivalence, ambiguous loss, VT, CF, and burnout, and we have highlighted associated symptoms.

While research shows that staff grieve when patients die, included sources highlight HCPs’ struggle to balance professional distance, acknowledgement of grief, and emotional

---

**FIGURE 1.** Leverage points and expected outcomes.
expression. Not being able to resolve this struggle can intensify the experience of disenfranchised grief.

Excessive task orientation is highlighted when HCPs have difficulty shifting from the task of saving the patient to consideration of other possibilities; when donation coordinators focus on donation-related tasks without showing openness with the treating team; when ICU staff focus on care of the potential donor and miss opportunities for family care; and when transplant surgeons and OT staff focus on surgery while neglecting their relationship or the need for shared meaning.

On the other hand, compassionate interaction with the family and collaboration within the multidisciplinary team were highlighted as factors crucial to staff members’ meaningful adjustment and appreciation of the synergistic system.

We propose that this theme can be activated by (1) offering training that assists staff to balance task orientation with attention to relationships and other psychosocial features of the context; (2) implementing care strategies for staff to improve their ability to cope with grief and role-related stressors; and (3) creating opportunities for feedback and shared learning to foster understanding, trust, and appreciation of the synergistic system.

Figure 1 (created using Kumu mapping software, https://kumu.io/) demonstrates how organizational inputs at these 3 leverage points could contribute to immediate outcomes influencing role players’ understanding and behavior and emerging outcomes on the level of the system as a whole. Although it is possible to include additional connections between factors or additional factors in our diagram, we feel that for the purposes of clarity, those shown are sufficient. The leverage points are explored in more detail below:

**Box 3: Effective connections contribute to a supportive environment**

Working in this context can be both stressful, contributing to physical, affective, and emotional symptoms, and rewarding, contributing to professional and personal growth. By monitoring the quality and quantity of connections between members of the multidisciplinary team, HCPs can assist each other to tolerate ambiguities and find novel solutions, contributing to a supportive environment and a balance between psychosocial care and attention to other important tasks.

The nature of relationships between role players influences service quality and other emerging outcomes. Seven key characteristics of relationships in successful systems have been identified as trust; openness to new ideas; attending to relevant tasks while appreciating the impact of one’s actions; respectfulness; tolerance of diverse perspectives; relationships based on a blend of personal, social, and work-related dimensions; and using communication that fits (in ambiguous situations face-to-face communication is advised, and language should be clear and jargon free). To activate these features, *reflection, meaning making, and openness to continual learning* are also necessary. Staff should continually ask themselves, “How is this affecting me?” and “How is my behavior affecting others?”

Following the death of a relative (and patient), and at other times when there are significant changes in the goals and activities of the system, families (and HCPs) no longer experience stability, and encounter the edge of chaos, where it is necessary to shift goals and hopes. Systems that function successfully on the edge of chaos are neither too stable nor too unstable and can tolerate incongruence while new paths are created and tested.

At this time, the quantity of connections between role players, their tasks, and other members of the multidisciplinary team influences system functioning. While systems with too few connections may become stuck and have difficulty adapting, systems with too many connections may experience an overload contributing to the lack of stable patterns. For example, information sharing between team members may become inconsistent at times when many tasks simultaneously demand attention. This could occur after a family has consented to donation, and nursing care of the potential donor intensifies, while at the same time increased negotiation with transplant teams and OTs is required.

Research suggests that for optimal functioning in complex systems, each party should be significantly connected to only 2 or 3 others at a given time to reduce the risk of overload or distraction from key tasks and opportunities. Training and resources should equip role players to carefully decide where to invest their attention and effort for maximum benefit, and team members must work together in a sustainable way. For example, support coordinators should play a greater role in relation to the family when donation coordinators and nurses need to attend to logistical priorities but can step back and enable other staff to be involved in family care when this is suitable.

**Care Strategies for Staff**

**Box 4: Provision of care for staff working in this context is vital**

Care and support to assist staff to cope with grief and other stressors can be offered on the level of the organization (including training, support groups, and debriefing sessions), the team (including mentoring and emotional support), and by the promotion of individual strategies such as finding meaning in family care, self-reflection, and expression of grief.

To create a supportive environment, staff must work collaboratively, support each other, and access support individually. In addition to reducing the impact of the death on HCPs, expression of grief can allow them to function more effectively, increasing professional and personal satisfaction. It has been suggested that organizational support, peer or team support, and personal coping strategies are helpful, especially in response to patient deaths early in a HCP’s career.

Organizational responses to HCP grief could include assisting staff to manage and diversify their workload, access to flexible scheduling, and attending support groups or debriefing sessions. An important aspect of psychological debriefing sessions is the expertise of the facilitator who...
should have training in group processes and bereavement care as well as knowledge of the organ donation context.154

Within specific teams, supervisors must receive training to enable them to recognize and respond to HCP grief and stress by offering support or making referrals.100,141 Psychosocial support and a caring mentor foster self-awareness and professional development, assisting HCPs to find meaning in their contribution to patient and family care. Peer support with colleagues who shared the experience is also meaningful.37,141

On an individual level, when compassion is experienced and shown without attachment to an eventual outcome (eg, survival of the patient), HCP adjustment is fostered by the realization that they can make positive contributions even if the patient dies.155 Organizations should provide access to individual counseling independent of the work environment, because social support may not be effective for those dealing with a personal trauma history.

Creating Opportunities for Feedback and Shared Learning

**Box 5: Empathy and understanding between role players enhance outcomes**

We argue that when members of the multidisciplinary treating team understand each other’s actions and stressors, the emergence of trust, empathy, respect, and collaboration will contribute to improved outcomes for all involved. Increased monitoring of psychosocial features relevant to family members and staff is expected to contribute to personal growth and the effectiveness of the system as a whole.

Researchers suggest that experiences of staff from different disciplines need to be connected enabling appreciation of the bigger picture,10,44 shared learning,154 empathy, and trust between HCPs.7,154 Trust and empathy would then, in turn, foster collaboration and consistency in relationships.35,60,117,158-161

When organ donation has occurred, a de-identified report about the transplants may assist HCPs’ meaning making,6,27,121,145,157,162 and receiving feedback from the family of the donor about their experience has been found to be valuable.26,100,309,163,164 Family feedback would also be useful when cases do not conclude with consent and organ donation. Sharing information about their experiences can be meaningful for family members too, enabling them to show gratitude for compassionate care, to make sense of their experience, and to contribute to improvement of in-hospital processes, thereby helping others.163-165

In addition to promoting improved service delivery, a follow-up meeting can be meaningful for HCPs and family members on a personal level.57 This fits with the view that for vicarious posttraumatic growth to occur, HCPs must be exposed to the family’s growth114 and is supported by findings indicating that many family members appreciate meeting HCPs a few months after the death to review in-hospital events.166,167

Outcomes of the in-hospital process are often measured in terms of consent rate (proportion of families consenting to donation in relation to families approached). However, because this provides a simplistic view,6,91 additional measures are needed to enhance understanding and ensure that adjustment and growth are promoted.4 Outcomes monitored should include interpersonal81 and staff-related factors such as role stress,4 collaboration in the multidisciplinary team, and support provided in response to staff grief.36 The extent to which HCPs have assisted family members to manage acute stress, find hope, and make informed decisions is an important outcome too.20,57,91

**Strengths and Limitations**

This review combined a multidisciplinary authorship team and a wide range of peer-reviewed sources to illuminate the CAS forming when a potential organ donor is identified. The synthesis will assist staff and organizational decision makers to make sense of and respond to grief and stress in ways that foster coping and growth for families and HCPs.168 However, although originating in various countries, only English sources were used, and the impact of culture and religion was not explored. The synthesis is based on a blend of published empirical evidence, theory, and the authors’ understanding of the context. Further research is needed to test our hypotheses.

Offering bereavement care (for family members and staff) tailored to this unique context emerged as a shared goal in the multidisciplinary team. However, a guiding theoretical framework is required, and the actual nature of a specialized bereavement support program must be determined.

The chosen scope of this article included illuminating the links between in-hospital factors (such as balancing attention to technical tasks and psychosocial features, providing family support, developing staff confidence, and encouraging collaboration between staff) on the one hand, and staff members’ adjustment to the patient’s death and their professional roles on the other hand. The effect that these factors can have on the family’s ability to cope with the death of their relative and other aspects of the in-hospital process was also explored. Studies have demonstrated that support provided by a trained coordinator throughout the in-hospital process can contribute to an increase in consent rates too.169,170 We did not explore this connection, and further research could be conducted to determine how the variables and outcomes that we have highlighted are related to consent rates.

The scope of the article was also limited to an exploration of in-hospital processes. In addition to optimizing this context, researchers highlight the need to understand how events at the hospital influence the bereavement of families in the months that follow,168 including declining families127 and consenting families, where donation did not proceed.11,19,101 Likewise, patient deaths can be expected to influence HCPs for some time after the family has left the hospital. However, the long-term impact of in-hospital experiences on family and staff well-being has received little attention,7 and research on follow-up programs is scarce.13 Attention to these areas will improve understanding of family and staff needs and promote improved care for both groups.

**CONCLUSION**

The identification of a potential organ donor contributes to a dynamic context that has implications for family members and HCPs. The cause of death, the family’s reaction, the need to attend to technical and logistical tasks, and other stressors shape staff members’ experiences, potentially increasing the risk of VT, CF, or burnout. This context also contains
opportunities for meaning making, purposeful action, and support. Implementing care strategies and empowering HCPs by providing education and training in bereavement care, self-care, and other psychosocial features will contribute to resilience, while appreciation of the systemic nature of institutional processes will foster shared learning and mutual understanding. We hypothesize that this can empower role players to make nonreactive decisions and respond in ways that fit on the day and contribute to ongoing adjustment.

ACKNOWLEDGMENT

The valuable input of the anonymous reviewers is acknowledged.

REFERENCES

1. Jacoby LH, Breitkopf CR, Pease EA. A qualitative examination of the needs of families faced with the option of organ donation. Dimens Crit Care Nurs. 2006;24(4):183–189.
2. Lloyd-Williams M, Morton J, Peters S. The end-of-life care experiences of relatives of brain dead intensive care patients. J Pain Symptom Manage. 2009;37(4):659–664.
3. Manuel A, Solberg S, MacDonald S. Organ donation experiences of family members. Nephrol Nurs J. 2010;37(3):229–236; quiz 237.
4. Dodd-McCue D. Behavioral research in hospital settings: the family communication coordinator (FCC) protocol and research applications in organ donation. In: Siegel J, Alvaro E, editors. Understanding Organ Donation: Applied Behavioral Science Perspectives. Chichester, UK: John Wiley & Sons; 2010:149–163.
5. Smith Z, Leslie G, Wynaden D. Coping and caring: support resources integral to perioperative nurses during the process of organ procurement surgery. J Clin Nurs. 2017;26(21–22):3305–3317.
6. de Groot J, Vernoij-Dassen M, Hoedemaekers C, et al. Decision making by relatives about brain death organ donation: an integrative review. Transplantation. 2012;93(12):1196–1211.
7. Kentish-Barnes N, Siminoff LA, Walker W, et al. A narrative review of family members’ experience of organ donation request after brain death in the critical care setting. Intens Care Med. 2019;45(3):331–342.
8. Lee YY, Ranse K, Silvester W, et al. Attitudes and self-reported end-of-life care of Australian and New Zealand intensive care doctors in the context of organ donation after circulatory death. Anaesth Intensive Care. 2018;46(5):488–497.
9. Hoover SM, Resar-Raikes DL, Roach E, et al. Parental experiences and recommendations in donation after circulatory determination of death. Pediatr Crit Care Med. 2014;15(2):105–111.
10. Smith Z, Leslie G, Wynaden D. Australian perioperative nurses’ experiences of assisting in multi-organ procurement surgery: a grounded theory study. Int J Nurs Stud. 2015;52(3):705–715.
11. Ahmadian S, Rahimi A, Khaleghi E. Outcomes of organ donation in brain-dead patient’s families: ethical perspectives. Nurs Ethics. 2019;26(1):256–269.
12. Ashkenazi T, Cohen J. Interactions between health care personnel and parents approached for organ and/or tissue donation: influences on parents’ adjustment to loss. Prog Transplant. 2015;25(2):124–130.
13. Bernsten H, Bjork IT. Experiences of donor families after consenting to organ donation: a qualitative study. Intensive Crit Care Nurs. 2014;30(5):266–274.
14. Cleeremans M, Van Zelelen AA. Post-mortem organ donation and grief: a study of consent, refusal and well-being in bereavement. Death Stud. 2002;26(10):837–849.
15. Jensen A. Searching for meaningful aftermaths: donor family experiences and expressions in New York and Denmark. Sifos. 2011;8(1):129–148.
16. Kesseling A, Kainz M, Kiss A. Traumatic memories of relatives regarding brain death, request for organ donation and interactions with professionals in the ICU. Am J Transplant. 2007;7(1):211–217.
17. Sque M, Payne S. Organ and Tissue Donation: Exploring the Needs of Families. Final Report of a Three-year Study Commissioned by the British Organ Donor Society, Funded by the National Lottery Community Fund. Southampton: University of Southampton; 2003.
18. Walker W, Sque M. Balancing hope and despair at the end of life: the contribution of organ and tissue donation. J Crit Care. 2016;32:73–78.
19. Manzari ZS, Mohammad E, Heydari A, et al. Exploring families’ experiences of an organ donation request after brain death. Nurs Ethics. 2012;19(5):654–665.
20. Smudla A, Hegedűs K, Mihály S, et al. The HELLP concept - relatives of deceased donors need the help earlier in parallel with loss of a loved person. Ann Transplant. 2012;17(2):18–28.
21. Smudla A, Mihály S, Okoró S, et al. The attitude and knowledge of intensive care physicians and nurses regarding organ donation in Hungary—it needs to be changed. Ann Transplant. 2012;17(3):93–102.
22. Thrisk LM, Moules NJ. “I can just be me”: advanced practice nursing with families experiencing grief. J Fam Nurs. 2013;19(1):74–98.
23. Kim HS, Yoo YS, Cho OH. Satisfaction with the organ donation process of brain dead donors’ families in Korea. Transplant Proc. 2014;46(10):3253–3256.
24. Kentish-Barnes N, Duranteau J, Montcalm C, et al. Clinicians’ perception and experience of organ donation from brain-dead patients. Crit Care Med. 2017;45(9):1489–1499.
25. Macovean E, Yuen EY, Tooey G, et al. Attitudes of intensive care and emergency physicians in Australia with regard to the organ donation process: A qualitative analysis [published online April 4, 2018]. J Health Psychol. doi: 10.1177/1359105318756619.
26. Pelletier-Hibbert M. Coping strategies used by nurses to deal with the care of organ donors and their families. Heart Lung. 2010;39(1):230–237.
27. Smith Z, Leslie G, Wynaden D. Experiential learning not enough for organ procurement surgery: implications for perioperative nursing education. Transplant Proc. 2015;25(4):339–350.
28. Anker A. Critical conversations: organ procurement coordinators’ interpersonal communication during donation requests. In: Laurie MA, editor. Organ Donation and Transplantation. USA: Nova Science Publishers; 2013:189–221.
29. Siminoff LA, Traino MH, Gendendorf WM. Communicating effectively about organ donation: a randomized trial of a behavioral communication intervention to improve discussions about donation. Transplant Direct. 2015;1(2):1–9.
30. Siminoff LA, Marshall HM, Duncill J, et al. Communicating effectively about donation: an educational intervention to increase consent to donation. Transplant Proc. 2009;41(1):35–43.
31. Simpkin AL, Robertson LC, Barber VS, et al. Modifiable factors influencing relatives’ decision to offer organ donation: systematic review. BMJ. 2009;338:b991.
32. Stouder DB, Schmid A, Ross SS, et al. Family, friends, and faith: how organ donor families heal. Transplant Proc. 2009;41(4):358–361.
33. Walker W, Sque M. Family bereavement: a case study of controlled organ donation after circulatory death. N Engl J Med. 2003;348(4):229–234.
34. Maloney R, Altoimaer C. Caring for bereaved families: self-efficacy in the donation request process. J Clin Psychohol Med Settings. 2003;10(4):251–258.
35. Moller N, Parker D, Hatcher D, et al. Grief experiences of nurses after the death of an adult patient in an acute hospital setting: an integrative review of literature. Collegian. 2019;26(2):302–310.
36. Papadatou D, Bellafi T, Papazoglou I, et al. Greek nurse and physician grief as a result of caring for children dying of cancer. Pediatr Nurs. 2002;28(4):345–353.
37. Fabian J, Cramble E. End-of-life care and organ donation in South Africa - it’s time for national policy to lead the way. S Afr Med J. 2017;107(7):11947.
38. Moghadam HY, Manzari ZS, Heydari A, et al. Explaining nurses’ experiences of caring for brain dead patients: a content analysis. Electron Physician. 2018;10(9):7205–7216.
39. Cramble F, Fabian J, Etheredge H, et al. Perceptions of nurses’ roles in end-of-life care and organ donation - imposition or obligation? S Afr Med J. 2017;107(7):573–575.
40. Cignarella A, Redley B, Bucknall T. Organ donation within the intensive care unit: a retrospective audit [published online February 19, 2019]. Aust Crit Care. doi: 10.1016/j.accu.2018.12.006.
41. Jordan ME, Lanham HJ, Crabtree BF, et al. The role of conversation in health care interventions: enabling sensemaking and learning. Implement Sci. 2009;4:15.
42. Manzano A, Pawson R. Evaluating deceased organ donation: a programme theory approach. J Health Organ Manag. 2014;29(3):366–385.
149. Safran DG, Miller W, Beckman H. Organizational dimensions of relationship-centered care. Theory, evidence, and practice. J Gen Intern Med. 2006;21 Suppl 1:S9–S15.
150. Ceyhan Ö, Özen B, Zincir H, et al. How intensive care nurses perceive good death. Death Stud. 2018;42(10):667–672.
151. Coetzee C, Van Niekerk D. Should all disaster risks be reduced? A perspective from the systems concept of the edge of chaos. Environmental Hazards. 2018;17(5):470–481.
152. Carroll T, Burton R. Organizations and complexity: searching for the edge of chaos. Comput Math Organ Theory. 2000;6(4):319–337.
153. Pelletier M. Role of organ donation in helping family members cope with grief. In: Morgan J, editor. Personal Care in an Impersonal World: A Multidimensional Look at Bereavement. New York: Baywood Publishing Company Inc.; 1993:157–166.
154. Rushton CH, Reder E, Hall B, et al. Interdisciplinary interventions to improve pediatric palliative care and reduce health care professional suffering. J Palliat Med. 2006;9(4):922–933.
155. Vachon MLS. Reflections on the grief of nurses. Grief Matters. 2012;15(1):8–12.
156. Keene EA, Hutton N, Hall B, et al. Bereavement debriefing sessions: an intervention to support health care professionals in managing their grief after the death of a patient. Pediatr Nurs. 2010;36(4):185–9; quiz 190.
157. Kelso CM, Lyckholm LJ, Coyne PJ, et al. Palliative care consultation in the process of organ donation after cardiac death. J Palliat Med. 2007;10(1):118–126.
158. Batten HL, Pratts JM. Kind strangers: the families of organ donors. Health Aff (Millwood). 1987;6(2):35–47.
159. Bellati L, Papadato D. Parental grief following the brain death of a child: does consent or refusal to organ donation affect their grief? Death Stud. 2006;30(10):883–917.
160. La Spina F, Sedda L, Pizzi C, et al. donor families’ attitude toward organ donation. The North Italy Transplant Program. Transplant Proc. 1993;25(1 Pt 2):1699–1701.
161. Willis R, Skelley L. Serving the needs of donor families: the role of the critical care nurse. Crit Care Nurs Clin North Am. 1992;4(1):63–77.
162. Michael GE, O’Connor RE. The importance of emergency medicine in organ donation: successful donation is more likely when potential donors are referred from the emergency department. Acad Emerg Med. 2009;16(9):850–858.
163. Giddings G. The ties that bind: a reflection on physician grief. Support Care Cancer. 2010;18(10):1355–1357.
164. Meert KL, Eggly S, Kavanaugh K, et al. Meaning making during parent-physician bereavement meetings after a child’s death. Health Psychol. 2015;34(4):453–461.
165. Alspar JG. Trauma, tragedy, and heartfelt thanks. Crit Care Nurse. 2013;33(5):9–12.
166. Downar J, Barua R, Sinuff T. The desirability of an intensive care unit (ICU) clinician-led bereavement screening and support program for family members of ICU decedents (ICU bereave). J Crit Care. 2014;29(2):311.e9–311.16.
167. Shih FJ, Lai MK, Lin MH, et al. The dilemma of “to-be or not-to-be”: needs and expectations of the Taiwanese cadaveric organ donor families during the pre-donation transition. Soc Sci Med. 2001;53(6):693–706.
168. Holmes BJ, Best A, Davies H, et al. Mobilising knowledge in complex health systems: a call to action. Evid Policy. 2017;13(3):539–660.
169. Jansen NE, van Leiden HA, Haase-Kromwijk BJ, et al. Appointing ‘trained donation practitioners’ results in a higher family consent rate in the Netherlands: a multicenter study. Transpl Int. 2011;24(12):1189–1197.
170. Witjes M, Jansen NE, van Dongen J, et al. Appointing nurses trained in organ donation to improve family consent rates [published online July 11, 2019]. Nurs Crit Care. doi: 10.1111/nicc.12462.