Conference paper

Family approach for organ donation and end of life discussions

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Abstract

End-of-life discussions in critical care are among the most challenging conversations that healthcare professionals must navigate. The addition of organ donation to these discussions amplifies the complexity. It requires balancing emotional distress (of families and staff), limited knowledge of individuals, cultural considerations, and varying family beliefs. These discussions require sensitivity, cultural awareness, and a deep understanding of both medical and ethical principles. The role of healthcare professionals in these moments is not only to provide medical care but to ensure that families are supported in a manner that respects their emotions, values, and ethical concerns.

Here we explore the challenges faced by families and healthcare staff when discussing organ donation, with an emphasis on best practices for improving communication and decision-making in the critical care setting.

Awareness of the challenges in organ donation discussions

Acknowledging the emotional and psychological stress of the discussion

Discussing organ donation with families in critical care settings is an emotionally charged and complex task, following the delivery of devastating news regarding a loved one's prognosis. Families, already in a state of profound distress, must navigate a series of medical, ethical, and emotional considerations while simultaneously coming to terms with their loss **(1, 2, 3)**. This cognitive overload and emotional turmoil often make comprehension and decision-making exceptionally difficult, particularly when faced with complex information, ethical concerns, and differing perspectives within the family.

These conversations take place in an overwhelming emotional landscape, where families are grappling with well-documented stressors such as shock, denial, guilt, and the struggle to reconcile medical realities with personal and cultural beliefs **(1, 4)**. Often the perceived suddenness of the situation exacerbates the psychological burden. Thus, healthcare professionals must approach these discussions with sensitivity, clarity, and structured communication to support families.

Likewise, healthcare professionals involved in these discussions also experience stress. This should not be underestimated; in doing so one runs the risk of failing to be in the best possible position to help families. Thus, they must balance empathy with clarity while managing their own emotional responses. Clinicians may feel a perceived urgency to facilitate a timely decision, especially given the logistical constraints of organ retrieval, but this time pressure rarely benefits anyone. Rushed discussions can lead to resistance, distress, or later regret, whereas allowing families space to process information fosters trust and informed decision-making **(1, 2, 5, 6).** Recognising these shared emotional challenges – both for families and staff – can help create a more compassionate, patient-centred approach that prioritises support over expediency **(4, 6)**

Understanding the problem: navigating complex vs. complicated issues

One of the challenges in managing communication around organ donation is recognising the nature of the problem itself. Problems in healthcare can be categorised as complicated or complex **(7)**. In the critical care setting, discussions about end-of-life care and organ donation present both complicated and complex challenges. Understanding this duality can aid clinicians in effectively navigating these conversations.

Complicated problems are those that, while intricate, are solvable with structured approaches, expertise, and best-practice guidelines. These are problems that can be broken down into sequential steps, with predictable outcomes if managed correctly (7). In the context of organ donation, examples include the logistics of donor management, such as ensuring organ perfusion, comprehending the medical criteria for donation, and adhering to the legal framework for consent. Clinicians can prepare for these aspects through comprehensive education and simulation-based training, ensuring they perform the "right thing well."

Complex problems, on the other hand, involve human behaviour, emotions, ethical considerations, and social factors. As a result, they are characterised by unpredictability and require adaptive and innovative approaches. The issue of family consent for organ donation is a prime example of a complex problem. Each family's situation and response to end-of-life discussions is unique, influenced by a myriad of factors including cultural beliefs, emotional distress, past experiences with the healthcare system, and personal attitudes toward death and donation. There is no one-size-fits-all solution, and outcomes are less predictable. These "wicked" problems necessitate healthcare professionals navigating these discussions with sensitivity, whilst remaining flexible, empathetic, and attentive to the evolving dynamics of the conversation, tailoring their approach to each family's needs and circumstances **(7).** Techniques such as active listening, open-ended questioning, and expressing empathy are vital in these scenarios **(5).** Active listening, a concept introduced by Rogers and Farson in 1957, emphasises the importance of fully engaging with a speaker to foster positive change and effective communication. Their seminal work, "Active Listening", outlines how understanding both the content and emotional undertones of a message, promotes deeper interpersonal connections **(8).** Further research has revealed that when individuals sense active listening during social interactions, there is enhanced neural activation in the ventral striatum.This suggests that being actively listened to is inherently rewarding, leading to positive emotional appraisal and improved impressions of the shared experiences **(9)**. This is likely to provide improved support for both families and staff. Thus, training for all staff in active listening could be a vital component of continuing professional development; improving the experience for both families and staff themselves.

Staff should recognise the interplay between the complicated and complex elements of these discussions when grieving families face a decision that is both emotionally and morally complex. This will allow them to develop appropriate strategies and better alleviate the inherent stress. Preparation and protocol adherence address the complicated aspects, while adaptive communication strategies and emotional intelligence cater to the complex ones **(1, 2, 5, 6).** This integrated approach not only enhances the effectiveness of the conversation but also supports the emotional well-being of both the family and the healthcare team **(10).**

Communicating with families

Organ donation conversations are inherently challenging. Understanding the multiple factors in play allows healthcare teams to anticipate and address barriers proactively, ensuring a supportive and informed discussion.

Emotional distress and grief

The sudden and often traumatic nature of a critical illness leading to death leaves families in shock, and grief profoundly affects a family's ability to process information about organ donation. Furthermore, the discussion of organ donation follows the delivery of devastating news regarding a loved one's prognosis. This will compound grief and make decision-making in a limited timespan even more challenging **(1, 2, 5, 6)**. The cognitive overload and emotional burden can make comprehension difficult and contribute to refusals even when patients were supportive of donation during their lifetime. Without appropriate emotional guidance, families may feel overwhelmed **(11)**, which can hinder their ability to engage in meaningful discussions about donation **(1, 2, 5, 6)**.

Lack of knowledge about organ transplantation

A significant number of families (and indeed many staff) have limited knowledge of the organ transplantation process. These processes will differ across countries, even those which may appear to have similar social norms. The United Kindgdom and many European countries operate under an opt-out system, presuming consent for organ donation unless individuals explicitly opted out. The United States, Canada and Australia follow an opt-in model, requiring individuals to register their consent, with family approval playing a crucial role. These differing consent frameworks significantly impact organ donation rates and public engagement across regions **(12)**. However, research suggests that switching from an opt-in to an opt-out organ donation system alone does not significantly increase donor numbers and may even hinder efforts if not supported by complementary measures. Public education, healthcare infrastructure, and government support play a more crucial role in improving donation rates than policy change itself. Countries like Spain have succeeded by implementing systemic interventions alongside opt-out policies, wheareas Brazil saw a decline in donations after adopting opt-out without addressing structural barriers. For developing countries, socioeconomic disparities and limited healthcare infrastructure make opt-out models challenging to implement ethically and legally. Instead, strengthening existing systems, improving donor identification, and training healthcare professionals are considered more effective strategies for increasing donations and maintaining public trust **(13)**.

Despite public awareness campaigns by NHS blood and transplant (NHSBT) and the British transplant society (BTS), misconceptions persist in the UK regarding organ retrieval, allocation, and donor body integrity. Many families remain unaware of the organ donor register (ODR) or mistakenly believe that prior registration guarantees organ donation regardless of family wishes **(1, 3, 14)**.

Family refusals to organ donation may arise from misconceptions rather than outright opposition. Common concerns include fears that a declaration of death may be premature, worries about disfigurement after organ retrieval, distrust in the fairness of organ allocation, and anxieties about their loved one experiencing prolonged suffering. Additionally, misunderstandings about brainstem death – particularly the difficulty in grasping the concept of death while a loved one remains on life support – can further contribute to refusal.

Addressing this gap in understanding requires careful explanation from trained professionals, as families may decline donation simply due to misinformation. In the UK, this is best undertaken by specialist nurses for organ donation (SNODs). Studies indicate that family consent rates are significantly higher when SNODs are involved in the approach compared to when discussions are led solely by ICU physicians **(1, 3, 14).** This is important since families who agree to donation often report long-term satisfaction with their decision, while those who decline may experience regret **(3).** SNODs also play a crucial role in maintaining continuity of care, ensuring that families receive ongoing support throughout the process.

Social and cultural differences

Cultural and religious beliefs play a substantial role in a family's decision regarding organ donation, shaping their perspectives based on traditions, ethical values, and personal experiences. For some communities, donating aligns with their ethical and spiritual values. However, others may have specific rituals or prohibitions concerning death and the handling of the body, perceiving organ donation as incompatible with their faith or cultural norms. Moreover, some prioritise communal decision-making over individual autonomy **(14, 15)**. In the UK, studies indicate that south asian and black communities have lower consent rates for organ donation due to religious concerns, mistrust of the medical system, and a lack of culturally tailored discussions **(1)**. Families may distrust medical professionals due to fears that doctors may prioritize organ retrieval over patient survival, a concern often fueled by media portrayals and misinformation **(14)**. Insensitive or inadequate communication, such as perceived withholding of information or a lack of sensitivity in delivering bad news, can exacerbate mistrust, make families question medical motives **(6)**. This can lead them to feel excluded from critical medical decisions, fostering feelings of helplessness and reinforcing skepticism toward healthcare providers **(16)**. Poorly handled donation requests and inadequate emotional support further reinforce skepticism, highlighting the need for specialised communication training to build trust **(5)**. Furthermore, perceived systemic racism and historical medical exploitation have contributed to deep-seated mistrust, particulary among minority communities, where past medical practices have left lasting concerns about fairness and transparency in healthcare **(17)**. Additionally, negative personal or vicarious experiences, such as prior encounters with medical errors or perceived neglect, can significantly diminish trust in the healthcare system, making families more hesitant to engage in discussions about organ donation **(18)**. Healthcare professionals must be attuned to these differing perspectives, ensuring that discussions are conducted with cultural sensitivity and aligned with the family's values and beliefs **(1, 15).** By recognising the underlying factors contributing to mistrust, they will be better prepared to engage in discussions more effectively, using culturally competent communications strategies that foster trust. This will make families feel heard and respected, ensuring their active involvement throughout the decision-making process.

Varying family views and decision-making dynamics

Within a single family, opinions on organ donation may also vary significantly, particularly when the deceased's wishes were never explicitly documented **(3, 15)**. Family disagreements can be exacerbated by generational gaps, differing moral perspectives, or distrust in the medical profession **(1, 14).** Individuals also process grief and make decisions at varying rates, necessitating flexibility in communication strategies. Disagreements among family members can add further strain when already grieving, leading to delays or even refusals. This is particularly sad when a patient was registered as a donor **(3, 15)**. In the UK, the Human Tissue Act (2004) ensures that a patient's consent is legally binding, but in practice, clinicians frequently defer to family wishes so as to avoid conflict **(1)**.

Studies have shown that families who have previously discussed organ donation are more likely to consent **(14)**. Encouraging open discussions about end-of-life decisions in primary care settings and during hospital admissions can contribute to greater acceptance of organ donation **(1).** In cases where the deceased's wishes are unknown, healthcare teams must carefully navigate family dynamics to ensure that decisions are made ethically and respectfully **(14)**.

Time constraints and the pressure of urgency

The time-sensitive nature of organ donation adds another layer of complexity to these discussions **(14)**. While families need time to process their grief and understand the implications of donation, medical teams must sometimes work within strict timelines to ensure organ viability **(14)**. This contrast between the urgency of medical procedures and the time families need to make informed decisions can create pressure on both medical teams and relatives. In contrast, once a decision is made, some families just wish 'everything to be over', leaving little time for the practicalities involved in retrieval team engagement. Multidisciplinary healthcare professionals must strike a delicate balance within their teams, providing families with the space and support they require, while ensuring that donation remains a viable option **(1, 3)**.

Healthcare professionals' discomfort

For many critical care clinicians, initiating discussions about organ donation can be daunting **(19)**. They may feel unprepared or uncomfortable, fearing that the conversation may be perceived as intrusive or coercive. Training for many staff groups frequently focuses on factual information, rather than the so called 'soft skills'. This can leave staff who are used to knowing 'the right answer' feeling unclear how to deal with the uncertainties of discussions with grieving families.

Furthermore, some clinicians find it challenging to 'pass control' of difficult discussions on to other members of the team (**20**). In the UK this may result in fewer donations, since evidence shows that SNODs are more likely to achieve family agreement for donation **(1, 3, 14).**

Recognising our goals

The "why" of the conversation

Before delving into how we approach these conversations, it is crucial to be clear about *why* they matter. Understanding and articulating this "why" provides a stable foundation even in unpredictable situations. The key motivations for these discussions include:

1. **Respecting the wishes of the patient** – Whether the patient has explicitly expressed a desire to donate organs or has left no clear directive, the conversation must centre on honouring their autonomy, values and dignity.
2. **Supporting the family** – Families are navigating profound grief and distress. However, in the longer term, families who donate their loved ones' organs have more positive outcomes. Therefore, the conversation should not only focus on the donation itself but also provide them with clarity, support, and a space for processing their loss.
3. **Recognising the societal need** – Organ donation is a communal act that transcends the individual. By facilitating the process, clinicians contribute to a broader ethical and medical imperative.
4. **Saving and transforming lives** – The recipients and their families are an unseen yet essential part of this conversation. Each organ donation represents a second chance for multiple individuals who might otherwise face terminal conditions.

The known/unknown matrix

In February 2002 Donald Rumsfeld, the US secretary of state described what has now become known as the "known unknown matrix", However, scientific enquiry has always proceeded along the path of enquiry of unknown outcomes. In most instances individuals believe outcomes will be from a known range of possibilities (known unknowns). But on occasion, a truly surprising outcome is found (unknown unknowns) **(21)**. Similarly, when undertaking social discussions of any nature, we may discover things we had not predicted. Therefore, it may be helpful to consider categorising our knowledge into four quadrants:

- **Known knowns** – Things we know that we know.
  The facts we can prepare for.
  These encompass established medical and legal aspects of organ donation, including patient eligibility criteria (e.g., neurological criteria vs. circulatory criteria for diagnosis of death), the legal framework (such as the Human Tissue Act in the UK), family consent processes, ethical considerations **(15)**, and strategies for delivering sensitive information in a structured manner **(1).**
  Example: A clinician explaining to a family that their loved one had already expressed their donation wishes through an advance care plan, or a conversation documented by

a specialist nurse in organ donation (SNOD), emphasising the legal backing and ethical reasoning behind honouring this wish under the Human Tissue Act 2004

- **Known unknowns** – Things we know that we do not know.

  The predictable challenges.

  Aspects we know might arise but cannot fully anticipate before the discussion, including the family's emotional response, their awareness of the deceased's donation wishes, cultural or religious influences **(1, 14)**, and potential disagreements among relatives. While clinicians can anticipate distress, uncertainty, or even anger, they cannot predict the exact nature or intensity of each family's response **(2, 5, 14)**

  Example: A family might not have discussed organ donation before, leading to uncertainty about their loved one's wishes.

- **Unknown knowns** – Things we do not realise we know.

  The tacit knowledge of clinicians.

  All healthcare professionals possess implicit knowledge that guides their approach to organ donation discussions. This includes intuition in delivering bad news, interpreting nonverbal cues, managing family conflicts, and recognising when to provide additional time before introducing donation. These implicit skills emerge as clinicians gain experience and may not always be recognised formally but play a critical role in guiding sensitive discussions.

  Example: An experienced clinician might sense that a family is not ready to hear about organ donation immediately after receiving bad news. Instead of rushing into the discussion, they allow for a pause before revisiting the topic. However, other families may need to move forward in a less interrupted manner.

- **Unknown unknowns** – Things we do not know that we do not know.

  The unpredictable variables.

  These are the most challenging aspects of communication because they encompass the most unpredictable elements. These might include sudden legal changes, unfamiliar cultural beliefs, unique family dynamics, or unexpected personal triggers for the clinician that can influence decision-making in unexpected ways. **(2, 14, 22)**.

  Example: A family may react with unexpected hostility due to a previous negative experience with the healthcare system, which influences their decision about organ donation. Alternatively, a clinician may themselves suddenly feel unexpectedly sad when a family comment leads to resurfacing of personal loss.

Integrating the complicated and the complex

By understanding the dual nature of these conversations – both as structured, trainable complicated problems and as fluid, dynamic complex problems – clinicians can approach them with greater confidence and clarity. The "knowns" provide a roadmap for preparation, while the "unknowns" call for adaptability, emotional intelligence, and a firm grasp of the fundamental purpose of the discussion. Ultimately, it is this balance – between structure and flexibility, knowledge and humility – that allows for meaningful, compassionate, and effective conversations in the context of organ donation.

Planning for effective discussions

Ensuring that families fully understand the process, their options, and the implication of their decision is an essential aspect of providing equitable and compassionate care **(1)**. Thus, effective preparation is vital.

Preparing for the emotional stress of the conversation

Healthcare professionals must mentally and emotionally prepare for organ donation discussions, as these conversations can be intensely distressing for both families and clinicians. Recognising the emotional toll of delivering bad news is essential, as moral distress and emotional fatigue are common in healthcare staff, potentially leading to burnout if left unaddressed **(6)**. Engaging in self-care and peer support, such as team debriefings, reflective practice, and structured peer support mechanisms, can provide a crucial outlet for emotional processing and resilience **(4, 6)**.

Understanding this preparation through the known-unknown matrix allows clinicians to develop a structured approach to managing stress.

Alleviating the stress using the "knowns"

While much of the conversation is unpredictable, there are known factors that clinicians can actively prepare for, reducing stress for both the family and the healthcare team.

- **Training for challenging conversations** – Regular simulation-based training, role-playing, and exposure to real scenarios can help clinicians develop confidence and skill in managing discussions and establishing clear communication strategies to minimise confusion and distress. It will always be the case that consistency comes with practice. However, the time available for this training for most staff is limited. Thus, SNODs who undertake this work on a daily basis are likely to be more confident and skilful in undertaking these conversations. Engaging with them early will support clinicians and families alike.
- **Minimising common stressors** – There is good evidence from a range of workplaces that easily remediable factors can increase stress and errors. Thus, minimising the impact of hunger, anger, loneliness and tiredness (HALT) should reduce unnecessary burdens **(23)**. Anger is part of the normal grieving process and tiredness is almost inevitable when families are spending time in intensive care units. However, it will be important to ensure neither staff nor family commence these challenging discussions alone or when they have not had physical sustenance.
- **Recognising stress in others** – Acute stress reactions (ASRs) are defined by the International Classification of Disease as 'the development of transient, emotional, somatic, cognitive or behavioural symptoms as a result of an exposure to an event ….. of an extremely threatening or horrifying nature' **(24)**. They are a normal response to threat, both physical and otherwise. Since ASRs can make it difficult for individuals to function, military units across the globe have found ways to help others in the acute situation to support their colleagues. Viewing the UK adaptation (iCOVER) it is easy to see the analogy with staff supporting families during challenging conversations. Important training features are to provide: **i**dentification, **c**onnection, **o**ffering of commitment, **v**erification of facts, **e**stablishing order of events and **r**equesting (movement / decision) **(25)**. Staff should be aware of the need to provide such support for colleagues as needed.
- **Planning the timing and setting** – A quiet, private space, allowing adequate time for discussion, can prevent undue pressure and provide emotional clarity for all participants.

- **Collaborating with other professionals** – Involving SNODs, psychologists, or chaplains can provide comprehensive support to both the family and the staff, while ensuring a multidisciplinary approach **(1, 3, 6)**.
- **Anticipating multiple perspectives** – Before initiating the discussion, clinicians should prepare for different viewpoints from family members, recognising the potential for conflicting opinions and the need for mediation. Indeed, undertaking a 'team brief' **(26)** prior to the conversation is likely to support all staff.

Alleviating the stress using the "unknowns"

Despite all preparation, there will always be unknowns – elements of the conversation that cannot be predicted or controlled. Navigating these effectively requires a shift in mindset:

- **Trying to discover what the unknowns may be** – the use of the mnemonic WAIT (why am I talking) may help here. Time telescoping is known to occur, and this may be affected by many factors **(27, 28)**. Thus, if not cognisant of this staff may fail to give enough time for families to bring their worries to the fore.
- **Being open** – Acknowledging that healthcare professionals do not have all the answers allows them to approach the discussion with humility and authenticity. It is not only acceptable, but important to say, "I don't know, but I will find out."
- **Recognising personal biases** – It is vital that the medical team acknowledge their own personal biases so as to avoid inappropriate interactions. However, it will also be important to appreciate those of families and adapt communication styles accordingly.
- **Practicing kindness towards families and ourselves** – These conversations can be emotionally draining for all parties involved. Extending compassion to the bereaved family is essential. However, it is equally important to engage in self-compassion – recognising emotional limits and seeking support when needed.
- **Grounding in the "why"** – While uncertainty will always exist, being clear on the purpose of the conversation provides a steadying force. When in doubt, return to the core reason for the discussion – respecting the patient, supporting the family, and saving lives. This will help maintain focus.
- **Emphasising emotional intelligence** – In complex interactions, emotional intelligence is critical **(6, 29)**. This includes:
    - **Self-awareness** – Recognising personal emotional state and biases.
    - **Empathy** – Actively listening to and understanding the family's concerns.
    - **Social skills** – Facilitating a respectful and constructive conversation, even in emotionally charged situations.

By incorporating structured preparation, self-awareness, peer-support and continuous learning within the framework of this matrix, healthcare professionals can better manage their own emotional stress when undertaking organ donation discussions. Ensuring they have the tools, training, and support systems in place allows them to approach these conversations with clarity, resilience, and compassion, ultimately fostering more meaningful and informed decision-making for families **(1, 5)**.

Structured communication strategies

Effective communication in organ donation discussions requires a structured, patient- and familycentred approach that prioritises clarity, empathy, and sensitivity **(2, 15)**. Structure will help create an environment where families feel supported, informed, and empowered. Utilising established frameworks such as the COMFORT model **(5, 30)** or the GRIEV_ING protocol **(31)**, helps clinicians provide organised, compassionate and ethically sound discussions **(5)**. Ensuring the use of active listening in a safe space will provide families with the time and support they need to process decision-making during emotionally weighted moments **(1).**

A fundamental aspect of structured communication is the use of clear and compassionate language. Avoiding medical jargon and focusing on the patient's known wishes, values, and prior discussions about organ donation can help ground conversations in what matters most – the dignity and autonomy of the individual **(2, 5, 32).** Families may struggle to process information during moments of acute distress, so healthcare providers must deliver messages with care, ensuring that explanations are straightforward, patient-centred, and attuned to the family's emotional state **(6)**.

Active listening and emotional validation play critical roles in fostering trust so that individuals feel heard **(2, 5, 14)**. Families experiencing shock, guilt, fear, and uncertainty need time and space to process the gravity of their decision **(3, 6)**. By acknowledging these emotions and allowing families to ask questions at their own pace, clinicians can create a space where trust can develop, ultimately facilitating a more open and informed discussion. By avoiding the common tendency to fill a silence with speech (i.e. using the mnemonic WAIT) and verbally acknowledging pain can make significant differences in how families perceive conversations **(2, 14)**. These should not merely be about conveying medical facts, but rather about guiding families to come to their own difficult decisions. This requires respect and understanding.

Addressing cultural and spiritual beliefs

Engaging with patients and families in open-ended dialogues about their cultural and spiritual perspectives is crucial. Involving chaplaincy services or spiritual care advisors can provide support and ensure that care plans are both respectful and aligned with those values and beliefs **(1, 3, 6, 15)**.

In the UK, the Human Tissue Authority (HTA) provides guidance on culturally sensitive organ donation practices. Dialogue with faith leaders and community representatives is encouraged, to improve trust in the donation process **(33)**. It is clear that no faith mandates the avoidance of organ donation **(34)**. NHSBT's initiatives have successfully incorporated multi-faith perspectives into their outreach programs, increasing awareness and engagement within diverse communities **(15)**. This aims to improve the background beliefs and feelings well before families are faced with these challenging situations. However, it will still be helpful when conversations are planned to have the immediate support of the appropriate cultural communities to provide advice to the family.

Addressing common concerns and misinformation

The use of visual aids, scans, and specific medical explanations can help clarify concerns and avoid misinformation **(1, 14, 22).** By addressing fears with clear, factual information and empathy, healthcare professionals can alleviate anxiety and encourage informed decision-making. However, the fundamental issue is to ensure team awareness of any family concerns, by providing time for these to surface **(1, 5)**.

Overcoming language barriers

The UK is a multicultural population, with many families not having English as their first language. Miscommunication in these charged discussions can lead to distress, misunderstandings and even refusal of organ donation **(3, 5, 6)**. Thus, availability of professional interpretation services is a necessity if donor and recipient families are to receive an optimum service **(1, 5)**. Trained medical interpreters ensure that conversations remain accurate, sensitive, and aligned with ethical best practices **(6)**. Where family members undertake this role, they inevitably come with their own biases and emotional overlay. Providing written resources or educational videos in multiple languages makes information accessible to diverse communities, helping families feel supported and empowered in their decision **(1).**

Breaking bad news and transitioning to donation discussions

As with all communication it is important to recognise the diverse ways in which individuals most easily understand information. Some will require written notes, whilst others require diagrams or speech. Learning from educators, whose role is to effectively impart information (sometimes to the less than willing) may provide useful resources for staff in this challenging situation **(35)**. Utilising a range of tools within conversations can help the widest range of family members understand the issues under discussion.

Healthcare professionals must then carefully navigate the transition from breaking bad news to discussing organ donation. Best practice guidelines advocate for ‘decoupling’- separating the announcement of death from the organ donation discussion to allow families time to absorb their loss **(1)**, while also avoiding perceptions of conflict of interest **(32)**.

Early involvement of trained professionals and the role of specialist nurses for organ donation (SNODs) in the UK

A structured and multidisciplinary approach to these conversations enhances their effectiveness and sensitivity. Involving the multidisciplinary team (MDT) (including physicians, nurses and chaplains or cultural representatives) in planning the timing and method of the conversation is critical **(1, 2, 5)**. Providing psychosocial support, bereavement counselling, and access to palliative care teams can help families process their emotions more effectively **(5)**.

In the UK, SNODs play a vital role in supporting families, improving consent rates, and addressing cultural concerns. These professionals are specifically trained to handle such sensitive discussions, providing detailed explanations and offering emotional support, to ensure dignity in the donation process. They help in addressing cultural or religious concerns, coordinating with faith leaders if necessary, and providing reassurance about the dignified treatment of the donor body **(1).** Their role involves them in organ donation discussions on a much more regular basis than any other of the team members. It is unsurprising therefore that the outcomes when they are involved are improved.

Supporting families regardless of their decision

Respecting families' decisions,whether they consent to organ donation or decline, plays a crucial role in maintaining trust, upholding dignity, and providing emotional support during one of the most difficult moments of family life. Even when families choose not to proceed with donation, ensuring they receive compassionate bereavement support is essential in fostering a positive relationship with healthcare professionals and the donation system **(1, 5, 14)**.

Families who decline organ donation may later experience regret, particularly if their decision was influenced by misinformation or emotional distress at the time. Studies indicate that some families who refused donation initially wished they had more time and information to fully consider the implications of their choice **(3, 5, 14)**. To address this, healthcare professionals should ensure that families feel heard, supported, and reassured that whatever decision they make is respected without judgment.

Bereavement care should extend beyond the donation decision itself, including access to counselling services, follow-up support, and the option for families to reflect on their experience. This may be provided in many ways, but involvement of the primary care physician is likely to be helpful **(4, 5, 14)**.

By fostering a non-coercive, empathetic environment, healthcare teams can help families feel respected and valued, regardless of their decision. This not only mitigates emotional distress but also contributes to a more positive perception of the donation process, which may influence future attitudes towards organ donation within their communities.

Conclusion

Communicating with families about organ donation in the critical care setting is a delicate and complex task that demands a balance of empathy, clarity, and strategic planning. Families face these conversations in moments of profound emotional distress, compounded by grief, uncertainty, and cultural influences that shape their perceptions of organ donation. Ensuring that healthcare professionals are prepared and adaptable in these discussions is essential, as these moments not only shape the legacy of the donor but also offer hope to those in need for transplantation,

By applying the known unknown matrix, critical care teams can enhance their preparedness by solidifying their understanding of established medical and legal facts while anticipating predictable challenges that may arise during organ donation discussions (the known knowns and known unknowns). At the same time, they can acknowledge and refine their tacit knowledge (unknown knowns) – those intuitive skills and experiences that shape their ability to navigate sensitive conversations effectively. Most importantly, they must remain flexible and adaptable, ready to respond to unforeseen circumstances (unknown unknowns), whether a sudden legal change, an unexpected family reaction, or a previously unencountered cultural belief. This structured yet dynamic approach allows staff to engage families with confidence, empathy, and a deep understanding of the complexities surrounding end-of-life decisions.

The "why" of the conversation must always remain central. These discussions are not merely procedural but deeply ethical and personal. Ensuring patients' wishes are honoured while supporting families through an informed and meaningful decision-making process is challenging but vital. "Known knowns", such as the legal framework and medical criteria for donation, provide a foundation of certainty that clinicians can confidently communicate. "Known unknowns", including a family's emotional response or awareness of their loved one's wishes, require sensitivity and adaptable strategies. "unknown knowns", the tacit knowledge clinicians develop through experience, allow for intuitive adjustments, while "unknown unknowns", the unpredictable factors that can shape each conversation, necessitate flexibility and resilience.

To ensure conversations are conducted ethically, compassionately, and effectively, healthcare professionals must be equipped with structured training, multidisciplinary collaboration, and ongoing self-care to manage the emotional toll. Recognising the emotional fatigue and moral distress that can arise, healthcare teams should engage in peer support, team debriefings, and reflective practice to sustain emotional resilience. Dispelling myths, addressing fears with factual information, and prioritising culturally sensitive communication can help families feel supported rather than pressured. Additionally, public education on organ donation plays a crucial role in fostering awareness, reducing misconceptions, and ultimately improving consent rates.

By prioritising empathy, education, and preparedness, the healthcare community can guide families through one of the most difficult decisions they will ever face. They must ensure they sustain their own mental well-being to optimise such interactions. In doing so, they uphold the dignity of the donor, honour the family's wishes, and contribute to the lifesaving impact of organ transplantation, ensuring that loss is met with the possibility of new life.

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