



Research paper

Navigating the referral boundaries for organ and tissue donation: An interpretive description study

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ARTICLE INFORMATION

Article history:

Received 21 May 2024

Received in revised form

1 November 2024

Accepted 3 December 2024

Keywords:

End-of-life care

Intensive care

Organ and tissue donation

Referral

Nurses

Qualitative research

ABSTRACT

Background: The gap between organ availability and the number of people waiting for a transplant remains a major healthcare issue. Most transplanted organs and tissue are received from donors who have died in intensive care units (ICUs). To increase the number of donors, national guidelines and professional bodies in Australia support routine consideration of organ and tissue donation at the end of life. Referral to donation specialists is the first important step to explore a patient's donation wishes and consider the potential for donation, but practice is variable, and not all patients receiving end-of-life care in the ICU are referred.

Objectives: The aim of this study was to investigate health professionals' experiences of making a referral for organ and tissue donation in the intensive care setting and to identify barriers and facilitators that influence practice.

Methods: A qualitative research approach with semistructured interviews and interpretive description analysis methods was used in this study. Doctors and nurses from a single tertiary referral hospital in Australia who had worked in the intensive care setting were invited to participate. Content from interviews was analysed through a process of coding and inductive thematic analysis. Nine health professionals were interviewed.

Findings: A local protocol was in place to support multidisciplinary referral for organ and tissue donation; however, there were organisational barriers and referral misconceptions that discouraged clinicians to make a referral. Nurses felt disempowered to refer and had limited knowledge of what was required. Doctors supported nurses making referrals, acknowledging that the responsibility should be shared to minimise the chance that a referral will be missed. Donation specialist nurses provided valuable support for health professionals navigating the organ and tissue donation process.

Conclusions: Research outcomes suggest the need for greater interprofessional collaboration to support a more inclusive referral culture in the ICU to optimise opportunities for organ and tissue donation.

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1. Background

In Australia, like the rest of the world, the need for transplantation exceeds the availability of donor organs. There are about 1800 people in Australia on the organ transplant waiting list and an additional 14 000 people requiring renal dialysis, many of whom could benefit from a kidney transplant.¹ Every year in Australia,

there are approximately 80 000 people who die in hospital and a small number of these patients (1250) will be suitable for organ donation.¹ Those patients who are eligible are mostly found in intensive care units (ICUs), and identification and referral to a donation specialist is the first important step to exploring the potential for organ and tissue donation. The literature indicates that identifying who could be a donor has been challenged by multiple issues, including inconsistent and complicated clinical triggers for referral^{2–4} and uncertainty regarding medical suitability.^{3,5}

To remove the ambiguity about patient eligibility for donation, national guidelines and professional bodies in Australia support a routine referral system. All patients who have been identified as

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experiencing end-of-life conditions which would result in their death are supposed to be automatically referred to trained donation specialists who have access to current suitability guidelines and consult with transplant teams.^{6,7} Many studies have identified that routine referral has made a significant increase to donation rates.^{8–10}

Equally important is the opportunity to explore patient donation wishes. Australia has an opt-in donation system, and people in the community can register their donation decision on the national Australian Organ Donor Register.¹ When a patient commencing end-of-life care is referred, donation specialists check the register for a donation decision to support further end-of-life planning.⁶ There is concern when a referral is not made that the decision of a patient who had registered their wishes on an organ donor register may go unrecognised, compromising patient-centred care.¹¹

Referral to a donation specialist is the first important step to explore a patient's donation wishes and consider the potential for organ and tissue donation. Australian guidelines^{12,13} support a routine referral system, and many health organisations have protocols in place. However, the literature suggests that not all patients receiving end-of-life care in the ICU are referred,^{7,14,15} and indeed local DonateLife audit data reflected a 60% referral rate in 2023.

2. Objectives

The aim of this study was to explore health professionals' experiences of making a referral for organ and tissue donation in the ICU and to understand the barriers and facilitators that influence practice. It is anticipated that the findings will generate new perspectives into how health professionals can be supported to improve healthcare delivery in organ and tissue donation services.

3. Methods

3.1. Design

A qualitative research approach using an interpretive descriptive approach was adopted to provide valuable insights into the experiences of health professionals involved in organ and tissue donation referrals. Interpretive description is particularly useful in exploring experience-based questions of interest as it captures the subjective realities of study participants who are, through purposeful sampling, the experts in the field.¹⁶

3.2. Participants

Before recruitment, Human Research Ethics Committee (H0027963) and state Department of Health Research Governance (SSA579) approval was obtained. Purposive sampling¹⁷ was used from a convenience sample of 230 doctors and nurses from the ICU to invite them to participate in the study. They were required to have worked in the intensive care setting for a minimum of 3 y and have had clinical experience with the process of organ and tissue donation. Doctors and nurses employed as donation specialists were excluded from the study. Participants were recruited by email, which was distributed via a third party. Participants who volunteered their time received consent forms and participant information sheets prior to consenting for interview. A total of six nurses and three senior doctors were interviewed. Participants' experience in the ICU setting ranged from 7 y to 35 y.

3.3. Study setting

Data were collected between June 2023 and August 2023 at a 500-bed tertiary referral hospital located in Australia. This hospital

offered specialised services including cardiac surgery, neurosurgery, and trauma. Within this facility, the mixed-specialty ICU, equipped with 33 beds, delivered comprehensive critical care, encompassing complex and multisystem life support for indefinite periods. The hospital was supported by a local DonateLife organ and tissue donation agency with a 24-h on-call service and a hospital protocol to support clinicians to make referrals. DonateLife receive around 75 referrals from the ICU in this hospital each year (local DonateLife Audit).

3.4. Data collection, analysis, and rigour

Data were collected through semistructured, face-to-face interviews held in a private room within the hospital. The interviewer was a colleague of the participants and had experience as a critical care and donation specialist nurse. Reflexive journaling and debriefing within the research team during data collection provided the opportunity to reflect on any concerns regarding data bias. The researcher was mindful not to lead or influence participants down a particular line of thinking. Interviews lasted around 45 min, and an interview guide (Table 1) was developed and pilot tested prior to use. The guide, with broad open-ended questions and prompts, was used to encourage free conversation whilst ensuring research aims were adequately covered.¹⁸ During interviews, the researcher paraphrased participants' answers to confirm the accuracy of accounts. Interviews were audio recorded and transcribed verbatim. A six-phase thematic analysis was undertaken to explore patterns across the data set.¹⁹ Thematic analysis was chosen for its flexibility to explore people's own perspectives and understandings and allowing an inductive orientation to the data. Further interviews were not required as no new data were found, thus reporting findings that have information power, which arose through qualitative data interpretation. This is in keeping with interpretive descriptive inquiry, which replaces the term data saturation with information power in applied research as it is about describing interpretively what the researcher learns and understands about the meanings of the practice situation.¹⁶

4. Findings

The research produced two main themes (Table 2). The first theme titled "Complexities hindering the referral process" has two subthemes "Organisational hierarchy" and "Referral misconceptions". The second main theme is titled "Facilitators assisting the referral process" and has three sub themes "Donation specialist nurses", "Procedural knowledge", and "Nurse-initiated referral".

4.1. Complexities hindering the referral process

Participants described the challenges they faced in referring potential donors. Despite hospital protocols designed to support decision-making and facilitate the process of referral for organ and tissue donation, there were barriers and misconceptions that hindered the process, making the system confusing and complex.

Table 1
Interview guide questions.

1. Describe a recent organ and tissue donation referral that you have been involved in.
2. Can you describe when a referral went well?
3. Can you describe when a referral did not go well?
4. Can you recall a case when a referral should have been made?
5. What do you consider is your role in the organ and tissue donation referral process?

Table 2
Themes arising from the data.

Theme	Subtheme	Codes
Complexities hindering the referral process	Organisational hierarchy	* Seeking permission from the consultant * Nurses prompt doctors to refer * I don't know enough about the patient
	Referral misconceptions	* A fear of getting it wrong
Facilitators assisting the referral process	Donation specialist nurses	* Familiarity provides a level of comfort * Approachable, accessible, and collaborative
	Procedural knowledge	* Exposure and experience build confidence * Education, review, and feedback
	Nurse-initiated referral	* Empower nurse to make referrals
		* Responsibility for referral should be shared

4.1.1. Organisational hierarchy

It was acknowledged by all participants that the consultant was the key decision-maker with the overall responsibility for determining when active treatment was no longer effective for a patient. Participants also agreed that when a patient's condition changed to an end-of-life care pathway, a referral to a donation specialist should be made. A protocol was in place to support multidisciplinary referral, but the data suggested that an organisational hierarchy existed that discouraged nurses to make referrals.

Participants reported that most referrals were made by the consultants and sometimes by senior registrars. Few participants could recall a nurse making a referral.

"I thought that it was very much doctor led ... I haven't seen nurses do the referral process" (P6 Nurse).

When nurses do refer, it is not seen as a positive event, with one participant recalling *"I do remember nursing staff getting very upset over the fact that the patient was not being referred ... and they [Nurse] eventually called DonateLife"* (P8 Doctor).

Participants identified variances in who they perceive is permitted to make a referral. The statement *"I don't know of any nurses making a referral ... are they allowed to?"* (P5 Doctor) suggests a differing understanding of organisational referral practices. Most nurse participants believed that they did not have the authority to refer, reflecting lack of agency to do so.

"I've had second thoughts about doing it [making a referral] because of not knowing if I was stepping on the medical staff's toes" (P3 Nurse).

Where nurses identified a patient to be suitable for referral, they performed "workarounds" to initiate the process. Participant 7 explains, *"I often prompt doctors if it hasn't been raised and no one's talked about it, but I have not made a referral myself"* (P7 Nurse). Nurses reported that they felt comfortable to contact the donation team to check if a referral has been made.

"I've definitely had conversations with them [DonateLife] just to see if they were aware of a certain case ... and if a referral has not been made, I can then talk to medical staff and say that it needs to happen" (P4 Nurse).

The data reflect that many participants do not feel confident to challenge a decision not to refer; this is highlighted in the statement *"I feel quite disempowered ... it's futile, the idea of me trying to refer, because they've told me that they have made the decision that it's not happening yet"* (P2 Nurse), and when decisions are questioned, it is undertaken with caution.

"I just found myself dancing around the issue of referral and having to choose my words very delicately" (P3 Nurse).

4.1.2. Referral misconceptions

Despite education and access to donation specialists, many participants were not aware of a protocol and that it supported multidisciplinary referral. Participant 9 stated, *"No, I'm not aware of a protocol, but I suspect there probably is"* (P9 Doctor). Perhaps because of this apparent lack of guidance and exposure to the referral process, nurses' practice has been hindered, and when questioned around the referral process itself, there was evident confusion as to what a referral entailed. Many nurse participants were unsure about what information was required when making a referral, with Participant 6 commenting *"I know the referral process would be quite a process, to make sure that all of the T's are crossed and I's are dotted ... do you have to fill out paperwork?"* (P6 Nurse). There was an assumption that decisions regarding medical suitability and timing for family donation conversation would be determined during this initial referral conversation. Based on this assumption, nurses reported hesitancy to refer because they felt that they did not know enough about the patient and family.

"I don't know the patients and their families well because I work part time ... I don't know the patient's complete clinical story, I felt that the medical team would know all that very well and would be better equipped with a decision around that" (P1 Nurse).

4.2. Facilitators assisting the referral process

In contrast to the complexities of making a referral, the data also showed that there were facilitators beyond protocols that supported health professionals in the intensive care setting to make a referral.

4.2.1. Donation specialist nurses

A positive relationship existed with the organ and tissue donation nurses who were described as accessible and approachable. This was highlighted in comments by participants who conveyed *"they just have such open communication ... there doesn't seem to be any barriers there ... I don't feel it is out of my place just to touch base ... the experience has always been really, really, good"* (P6 Nurse) and *"having the support of somebody from DonateLife and support with the donation process is really useful ... it is a lot more helpful to have somebody who is physically there"* (P9 Doctor). Many of the donation specialists had worked in the ICU and were known to participants.

"it helps having familiarity with the DonateLife staff because there's that level of comfort and understanding that makes it easier to make a referral" (P3 Nurse).

Visibility of donation specialists in the ICU was deemed important to participants and is reflected in the following statements: *“the DonateLife team are proactive, and I think they’re a bit more out and about and people see them ... I think having that relationship and seeing them often makes you think about it [referring] more”* (P7 Nurse) and *“... you have to be seen and keep talking about it ... knowing faces is a bit better rather than doing everything by remote”* (P5 Doctor).

4.2.2. Procedural knowledge

Nurses and doctors in the intensive care setting receive organ and tissue donation education facilitated by the organ donation team. Nurse participants shared that the Introductory Donor Awareness Training workshop and organ and tissue donation posters were effective resources, *“the posters are good ... there was a poster straight ahead and it certainly did prompt me to ask the question”* (P1 Nurse). Doctor participants reported that fortnightly morbidity and mortality meetings designed to review the quality of care being provided to patients are an important forum for clinicians to receive referral data and participate in discussions around missed referral. However, it was noted that attendance at these meeting could be improved and that multidisciplinary participation could be encouraged.

“it’s been really helpful having the DonateLife team in the room and being involved in the M&M ... it is all about quality improvement and raising awareness” (P8 Doctor).

Participants reported that actively participating in the referral process and collaborating with donation specialists built clinical knowledge and confidence to initiate a referral. This is best reflected in a comment by a participant who expressed *“the more we do it [make a referral], the better we’ll get at it”* (P4 Nurse).

However, opportunities to gain experience could be improved as the following narrative conveys:

“From the medical side of it, we should include trainees in the process more closely ... there’s always the opportunity to talk about that at teaching for the trainees, but I think the thing that’s missing is the opportunity to be directly involved ... making the referral and being responsible for communicating with other members of the team is something that could probably come a bit earlier in training” (P9 Doctor).

4.2.3. Nurse-initiated referral

Both doctors and nurses expressed support for nurses making referrals, with Participant 1 commenting *“I think an experienced nurse who has been involved with end-of-life discussions and decision making should be able to refer”* (P1 Nurse). It was thought that the responsibility should be shared to minimise the chance that a referral will be overlooked or that the process influenced by personal belief systems and conflicting priorities.

“I think it would be a great thing ... if we have more participation from other staff, particularly the nurse who’s at the bedside ... if nursing staff are proactive about it, I think that could potentially make the referral process a lot easier ... I think that might actually get things going ... raise awareness and increase the rate of referral” (P8 Doctor).

5. Discussion

The study objectives were to gain an understanding of the experiences of health professionals involved in referring patients for organ

and tissue donation. Despite emphasis placed on the importance of working as a team in many aspects of health care, hierarchical boundaries were identified that hindered practice and deterred clinicians from making a referral for organ and tissue donation.

Consistent with previous research,^{4,5,20} it was assumed by many participants that making a referral for organ and tissue donation was a medical responsibility. Furthermore, a culture of seeking consultant permission to refer was described by both nurses and doctors in training. As a result of this gatekeeping, most participants described situations when a referral was not made, or workarounds were put in place to alert organ donation specialists. Some suggested that an individual’s own belief systems were an influencing factor to not refer, an idea also supported in the literature.^{3,5,10} Hierarchical approaches to decision-making involving organ donor suitability have been identified in many studies^{5,7,20} and should be challenged in a time when patient-centred care and patient choice is a leading ideology of modern health care.¹¹

Local hospital protocols for organ and tissue donation contain scope beyond the responsibility of the consultant for referral to donation specialists. Doctors in training and nurses have legitimacy to refer; however, it is evident in this study that nurses especially did not feel confident to make a referral because of professional boundaries they felt they could not cross.

Power differences among interdisciplinary group members are firmly ingrained in health organisations. Status differences in health organisations are largely tied to professional identity and culture and are often linked to differences in education, knowledge, and expertise.²¹ These differences are growing smaller as nurses become more professionalised; however, despite the high level of education and significant responsibility nurses in the ICU have in caring for critically unwell patients, some felt powerless to challenge a decision not to refer. These findings align with suggestions that nurses experience uncertainty around their role in the organ and tissue donation process²⁰ because professional inequalities are still present, and nurses remain an “oppressed group”.²²

Imbalanced power relationships are maintained through attitudes and behaviours shaped by professional socialisation. Doctors are socialised and trained to become autonomous leaders, whilst nurses are trained in more collaborative models of care.²¹ There has been a strong push for healthcare professionals to work together through interprofessional collaboration to improve health care in an increasingly complex and fragmented health system.²³ Hierarchical boundaries that exclude or limit nurses from participating in patient care processes result in the underutilisation of skills and experience.²⁴ The United Kingdom and United States of America have notably higher organ donation rates than Australia.²⁶ Whilst this difference is influenced by multiple factors, collaborative practices such as nurse-initiated referrals for potential donors are common in these countries.^{20,25}

Active support from senior medical colleagues for nurse-initiated referral will work towards correcting traditional institutional hierarchy; however, advocacy from within the nursing profession itself must drive change to address such challenges in the healthcare system. Donation specialist nurses display leadership in interprofessional collaboration through their effective communication skills, willingness to share knowledge, and ability to overcome professional boundaries.^{23,27,28} Donation specialist nurses can lead efforts to promote a more inclusive referral culture by closing the knowledge practice gaps identified in this study and uniting healthcare teams to achieve a common goal.

6. Limitations

There are limitations to consider. This study involved a small number of health professionals from a single hospital in Australia,

and their experiences may not be representative of all healthcare settings. The interviewer was known to most of the participants, which may have constrained responses, and use of an alternative interviewer may have resulted in additional views. The findings may be specific to this region and may not be applicable throughout Australia or internationally. The study recommendations addressing the role of the nurse in organ and tissue donation referrals may best be applied to hospitals supporting routine referral at end-of-life care.

7. Conclusions

The aim of this study was to explore the experiences of health professionals involved in making referrals for organ and tissue donation. By identifying both barriers and facilitators, valuable insights into the factors that influence referral practices have been gained that offer recommendations for clinical practice.

Collaborative efforts should be made to build trust and share power between disciplines. Empowering nurses to perform at the full scope of their practice and confidently make referrals will not only help to prevent referrals being missed but also bring about a shift in traditional hierarchies. Establishing a clear process for nurse-initiated referral that is supported and actively encouraged by senior medical staff will foster a culture that values interdisciplinary collaboration. The responsibility of referral for organ and tissue donation can be incorporated into existing nurse leadership roles in the ICU. Leading by example and normalising nurse-initiated referral can encourage other nurses to participate and help alleviate any concerns or uncertainties they may have about the referral process.

Organ and tissue donation education should be delivered to health professionals as members of an interdisciplinary team. The content of education workshops should be reviewed to ensure relevance across disciplines, accompanied by enhanced opportunities and dedicated time for attendance. It is essential for nurses to understand their role in the referral process. Providing explicit education regarding the multidisciplinary approach and what happens after referral ensures that nurses understand the broader context and feel assured in their role within the referral process. A greater presence and educational initiatives from donation specialist nurses would be well received.

Further research investigating the impact of nurse-initiated referrals is warranted. This research could concentrate on strategies for enhancing collaboration between nurses and doctors and examine various nurse-initiated referral models.

Exploring patients' end-of-life donation wishes and maximising all opportunities for donation require health professionals in the ICU to refer all patients to donation specialists. Promoting a more inclusive and collaborative referral culture, particularly one that encourages nurse-initiated referral, may work towards achieving this goal.

Funding

This research was supported by a Department of Critical Care Medicine research grant. The funders had no part in the study design, conduct or data analysis and did not have any authority over these activities.

CRedit authorship contribution statement

KL: conceptualisation, project administration, methodology, investigation, data curation, formal analysis, writing—original draft, funding acquisition.

CW: conceptualisation, methodology, supervision, writing—review and editing.

MG: conceptualisation, methodology, formal analysis, supervision, writing—review and editing.

Conflict of interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this manuscript.

Data availability statement

The data that supports the findings of this study are available upon reasonable request from the corresponding author (KL). The data are not publicly available due to their containing information that could compromise the privacy of research participants.

Acknowledgements

The authors wish to thank the nurses and doctors who generously shared their time to participate in this study.

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