

Research Article

Exploring nurses' knowledge, attitudes and feelings towards organ and tissue donation after circulatory death within the paediatric intensive care setting in the United Kingdom: A qualitative content analysis study

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ABSTRACT

Objective: This study explored nurses' knowledge, attitudes and feelings towards donation after circulatory death identifying these domains as barriers and facilitators to nurses effectively undertaking their role in the donation after circulatory death donation process.

Design: A single-phase qualitative study design.

Setting: One paediatric cardiac intensive care unit in a tertiary paediatric hospital in England.

Methods: Data was collected from eight paediatric cardiac intensive care nurses using semi-structured face to face or telephone interviews facilitated by a clinical vignette. Qualitative content analysis was undertaken adopting both inductive and deductive lenses.

Key findings: Three categories were deductively generated within which eleven inductively generated themes were situated. Barriers included: knowledge deficits of both process and resources; assumptions about parental views and reluctance to facilitate sensitive discussions, facilitators included positive attitudes toward donation aligned with a strong professional ethos and family-centred values.

Conclusions: The paper identifies barriers to the donation after circulatory death process including nurses feeling unprepared for their role, anxiety over family approach and communication methods and support. Highlighted is the need for specific educational interventions, appropriate resources and development of paediatric focussed policy to guide practice. Facilitators to donation include timely, sensitive and appropriate family discussions, trusting nurse-family relationships and improved public awareness.

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Implications for clinical practice

- Provision of more donation after circulatory death education for both pre- and post-registration nurses.
- Education should include: information on the process of donation after circulatory death, resources available for families, typical questions families may ask and how best to respond to these.
- Education should be delivered as: written guidance and information (provided at national level), including the distribution of information for staff on how and when to appropriately contact organ donation services; Specialist Nurses for Organ Donation training days, including scenario-based simulation practice provided by hospital trusts, drop-in sessions with the trust and annual updates delivered through newsletters and internet sources.
- Availability of appropriate resources for staff and families to provide support through the donation process. Suggested resources include: information leaflets and availability of wider multi-disciplinary support.

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Introduction

Daily in the United Kingdom (UK), approximately 176 infants, children and young adults are waiting for a transplant operation due to the shortage of paediatric organs (NHSBT, 2017). The number of children waiting is neither static nor definitive as: patients are moved onto and off lists in response to changes in their clinical situation, and the fact that some children are not listed for transplantation when their medical practitioner considers the chance of an organ becoming available to be negligible (Rodrigue et al., 2008).

According to National Health Service Blood and Transplant (NHSBT) figures, due to the shortage of paediatric donors, over 900 children have waited for a kidney transplant over the past 10 years with an average waiting time of 2.5 years. Children waiting for a heart transplant will wait on average 2.5 times longer than an adult who is waiting (NHSBT, 2018). Low rates of paediatric organ donation is not only an issue for the UK as figures available for paediatric heart and lung donation from the Global Observatory on Donation and Transplantation (GODT, 2018) clearly report the discrepancy between the number of adult and paediatric transplant operations undertaken globally. GODT report that in 2018, 662 paediatric heart transplants took place as opposed to 7626 adult transplants with 99 paediatric lung transplants taking place as opposed to 5497 adult lung transplants.

The process of paediatric organ donation

In the UK and internationally Paediatric Organ Donation (POD) is facilitated within the context of paediatric intensive or critical care environments (from here on referred to as PICU). The reason for this is that the potential donor will be requiring life-sustaining interventions for example mechanical ventilation and multi organ support.

There are two donation trajectories, the first leading to donation following the determination of death following the irreversible cessation of brain stem function (DBD) and the second being donation following confirmation of death following permanent cessation of cardiorespiratory function (DCD) (ODTC, 2018). Donation following circulatory death (DCD) remains controversial in some paediatric institutions as this is a relatively new initiative introduced to try and increase the supply of organs for use in transplant operations. Internationally, some countries with donation programmes do not have DCD programmes, or focus on uncontrolled DCD. Currently the UK, Netherlands and Australia have well developed programmes with DCD in the UK currently supplying 39% of the organs needed in the adult programmes (ODTC, 2018).

The process of organ donation in both adult and paediatric programmes relies on: identification of a potential donor, (by health care professionals working in ITU/PICU), referral to the specialist team (Specialist Nurses in Organ Donation, SN-OD), approaches to relatives/decision-makers to discuss donation, gaining consent/authorisation for donation (from relatives/decision-makers), confirmation of death (DBD or DCD), donor management, the retrieval of organs and the post death care of the body. There is the potential for the loss of potential donors at each point along these donation trajectories (Fig. 1) resulting in very different numbers of paediatric donors with DCD (2017/18 = 17 donors) lagging behind DBD donation 2017/18 = 23 donors).

Why is paediatric DCD lagging behind DBD?

A consistent finding from a limited body of knowledge is that there is a perceived lack of knowledge and guidance, around Paediatric Organ Donation (POD), and DCD in particular, despite national

organisations; NHSBT, NICE, UKDEC (UKDEC, 2011), generating guidance over the past 5 years. Research, predominantly undertaken in the USA, has demonstrated that PICU healthcare professionals (HCPs) feel unprepared for their role in the DCD process. Reported barriers to facilitating donation via the DCD route include: concerns over poor knowledge of DCD protocols (Curley et al., 2007; Mathur et al., 2008; Kurz, 2014; Weiss et al., 2016), concerns regarding approaching family members and supporting them through donation (Mathur et al., 2008), communicating with families and other HCPs to gain consent to donation (Kurz, 2014; Weiss et al., 2016).

Authors in the Netherlands report generally positive attitude amongst nurses towards DCD (Siebelink et al., 2011), however the option of DCD raises personal conflicts for some nurses. Curley et al (2007) surveyed paediatric clinical staff in the USA seeking their views about whether a DCD program would be consistent with the mission and core values of a children's hospital. Data from 88 staff members gained from eight focus groups articulated concerns including the personal/professional tension that the issue of organ donation can trigger. One participant illustrated this tension: "On one extreme I feel like we are being asked to set up an organ bank business and on the other side... Protecting and saving life... a conflict of interest" (P: 214).

Empirical work carried out by Mathur et al (2008) in the USA exploring the perceptions, level of knowledge, and understanding of DCD in Paediatric Critical Care Nurses (PCRNs) surveyed 123 nurses with 93 (76%) PCRNs supporting organ donation, 69% reporting that donation gives meaning and worth to death, and 76% of participants reporting that they felt that donation contributes positively to the donating family's grieving process. However, 11% feared that the DCD donor feels pain and suffering and 14% felt that a 5-minute observation period after asystole is insufficient to pronounce death, and 8% feared legal repercussions.

Other concerns reported to act as barriers to DCD from US studies include: perceiving withdrawal of treatment as a professional failure (Harrison and Laussen, 2008), staff reluctance to accept DCD protocols due to ethical concerns over the protection of children; in particular that the decision to donate may lead to a premature decision to withdraw life-sustaining treatment (Antommara and Bratton, 2008; Weiss et al., 2016).

A further barrier is the perceived lack of clinical guidelines and protocols to support health care professionals in their decision-making and engagement with family members and other health care professionals despite published guidance (Weiss et al., 2016).

In view of the evidenced challenges to increasing paediatric donation rates via the DCD route, and in completion of a Master in Advanced Nursing Practice the following qualitative study was conducted with the aim of exploring nurses' knowledge, attitudes and feelings towards DCD within one paediatric cardiac intensive care unit in the South of England.

Research question

What knowledge, attitudes and feelings inform the practice of PICU nurses when donation after circulatory death is an option at end of life?

Study objectives

- To map critical care nurses' knowledge, attitudes and feelings towards paediatric DCD
- To identify barriers and facilitators to: identification of potential donors, referral to specialist teams and discussing the option of DCD with family members.

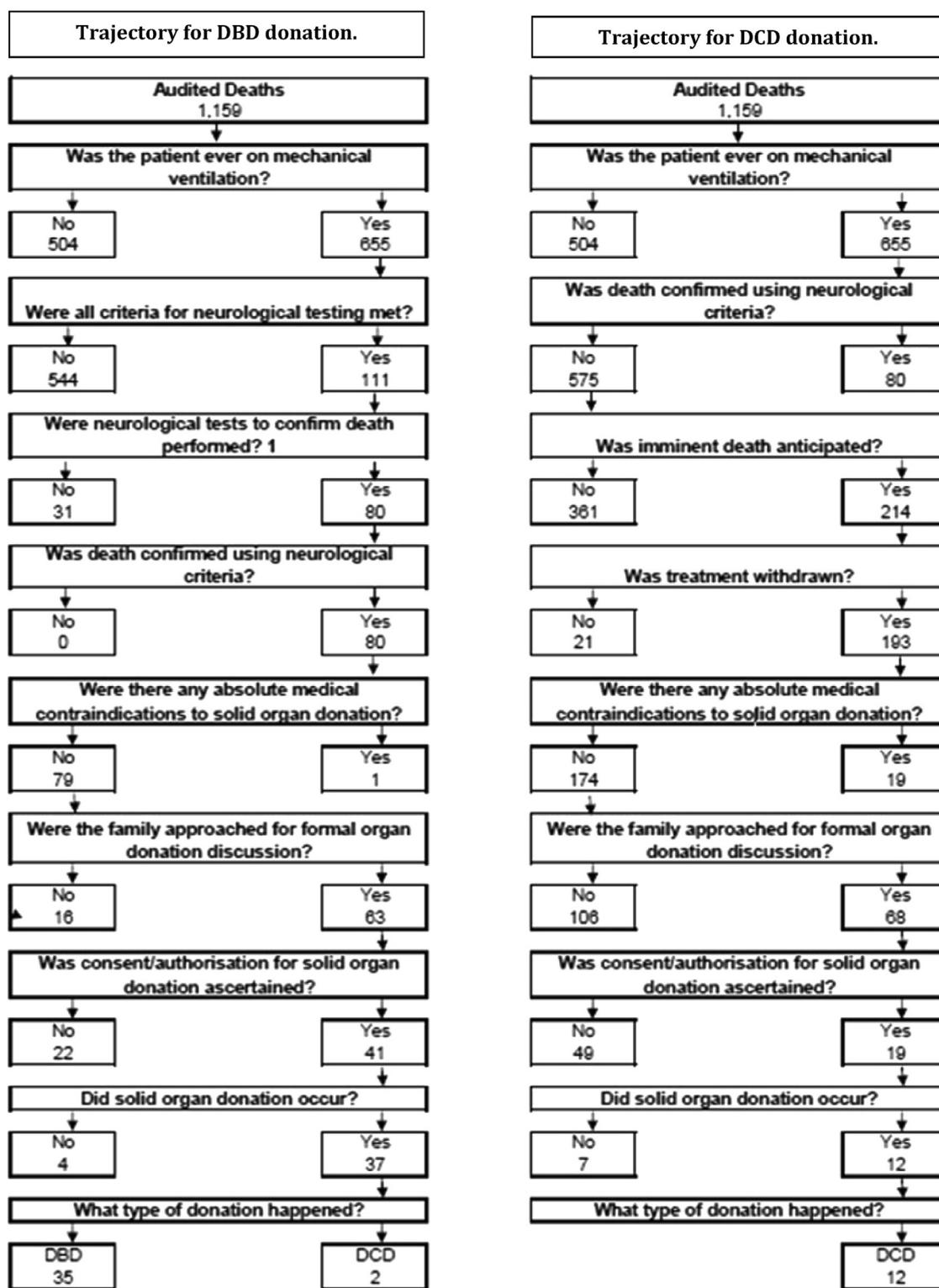


Fig. 1. Paediatric deaths in UK PICUs between 1st April 2016 and 31st March 2017 (NHSBT, 2018).

- To determine what support, education and organisational interventions, paediatric critical care nurses' need to confidently ensure consideration of DCD at end of life.

Study design

A single-phase study applying qualitative methods of inquiry was carried out with data collection being undertaken over a one-month period (February 2017).

Participants and recruitment

Nurses from one cardiac PICU in a tertiary paediatric hospital were invited to participate in the study. As nursing experience and knowledge have been identified as factors that may impact confidence a stratified sample (by nursing band 5 and 6 with less than one year and more than one year experience) was sought. The aim of recruitment was to gain a sample that included a maximum of eight nurses (sample size constrained by time line to

undertake the study for a master's dissertation, and the intention to carry out a rigorous and trustworthy study) who were most likely to have patient and family involvement. Current staffing levels indicated that 104 nurses held Band 5 and 6 positions and therefore the poster advertising the study clearly indicated the sample size being sought and the clarification that the first two respondents under each category would be included (if willing to continue post discussion with the researcher).

Thirty recruitment packs, including invitation letters and participant information sheets, were placed in the PICU staff room resulting in sixteen responses (15%). Table 1 illustrates participant demographic data. Participants' ages ranged from 21 to 44 years, all were female with at least a degree in nursing education. One participant (12%) had received formal DCD training as a nursing student and four (50%) had received this training post-registration.

Data collection

Interviews (lasting on average 30 min) either face to face (n = 2) or telephone (n = 6) (participant preference) were conducted by author SD after participants had provided written or verbal consent. Prior to interview, participants were asked to read a clinical vignette (Fig. 2) that had been developed to encourage exploration

of this sensitive topic from a hypothetical perspective (Reynold, 2002). The semi-structured interview schedule (Fig. 1) was developed from literature and expert opinion and focussed on eliciting three domains: knowledge, feelings and attitudes towards DCD.

Data analysis

Interviews were transcribed verbatim by SD with transcripts undergoing qualitative content analysis (QCA) (Elo and Kyngäs, 2008) by SD and TLS. The method was chosen as Krippendorff (2004) suggests this method facilitates the development of new knowledge and insights by building a conceptual map developed from applying both inductive and deductive reasoning. Deductive reasoning is informed by pre-determined themes and knowledge gained from literature reviewed, whilst inductive reasoning generates themes and categories from the raw data (Bengtsson, 2016).

Rigour and Trustworthiness

Trustworthiness was enhanced by maintaining a detailed audit trail throughout the project, comprising of field notes from initial thoughts through to analysis, accurate transcriptions, reduction and synthesis of raw data, and evidence of the analytical process.

Table 1
Participant demographic data.

Participant no.	Band	Years in role	Age	Gender	Level of Nursing Qualification	Formal Pre-Registration DCD training	Formal Post-Registration DCD training
OD1	5	2 years	24	Female	Degree	No	Yes
OD2	5	6 months	22	Female	Degree	Yes	No
OD3	5	2 years	22	Female	Degree	No	No
OD7	5	6 months	21	Female	Degree	No	No
OD4	6	10+years	44	Female	Masters	No	Yes
OD5	6	6 months	31	Female	Degree	No	Yes
OD6	6	6 months	29	Female	Degree	No	Yes
OD8	6	10+years	43	Female	Degree	No	No

Clinical Vignette: A one-year old boy, diagnosed with long-segment tracheal stenosis, is currently intubated and ventilated. He has been an inpatient on the unit for 11 months now following multiple failed interventions. The patient cannot be extubated, there are no further surgical options and the patient has now clinically deteriorated. Discussion with parents has led to the decision to withdraw life-sustaining treatment. In line with clinical guidelines, this patient was referred to the Specialist Nurse – Organ Donation (SN-OD) by the clinical team. Following review of this patient's clinical history, the SN-OD has indicated that the patient is a suitable candidate for donation after circulatory death	
Questions	Prompts
Does this scenario relate to any clinical cases you have experienced in the past?	If involved: In what capacity were you involved? What was your personal assessment of the process. Who took what role? Assessment of whether a positive experience for a) HCP b) the family?
Can you tell me about what the term DCD means to you?	In comparison to DBD? Where/How knowledge gained? How well informed would you say you are about DCD? What sources of information do you/have you drawn on?
If you were the nurse caring for the child in this scenario, what would be your next steps in terms of preparing the patient/ family for DCD?	What type of information is available. What contacts need to be made? What family focussed support available?
DCD rates in paediatric units are low in the UK. What do you think is contributing to this?	
What are your views about the option of DCD in Paediatric ICUs	Can you tell me about what has influenced your views?
Whose responsibility do you think it is: to identify potential donors, to raise the issue of DCD and support the family in this scenario?	How confident would you feel in answering family questions about DCD? Do you think that you need extra information, support, and education? If yes, who should provide this and how would you prefer to receive this?
Would you raise the issue of DCD with a patient's family?	Can you tell me what has influenced your decision?
Should DCD be offered to all patients/ families (provided they are suitable candidates) after the decision to withdraw life- sustaining treatment?	What do you think might prevent the issue of DCD being raised? What do you think supports the issue of DCD being raised?
If you were the nurse at the bedside in this scenario, can you consider how you might be feeling?	
The option of health care professional conscientiously objecting to being involved in donation processes has been proposed in recent literature, what do you think about the option conscientious objection in this situation?	Do you think that all nurses should have to take part in the DCD process?

Fig. 2. Clinical vignette and interview schedule.

Table 2
Data analysis approach.

Analysis Phase	Preparation phase	Organising phase	Reporting phase
Process	<ol style="list-style-type: none"> 1. Transcripts reviewed, identifying initial concepts and ideas. 2. Data sections annotated using a colour-coded system. Each colour represents a key theme identified throughout the scoping review (deductive reasoning process). 3. Transcripts are repeatedly reviewed; new ideas are identified (inductive reasoning process). 	<ol style="list-style-type: none"> 1. Ideas, concepts and themes identified throughout the literature review are given codes via deductive reasoning. 2. New ideas, concepts and themes identified in the initial preparation phase are given codes via inductive reasoning. 3. Coding sheets are developed and grouped into categories (using a categorisation matrix). 4. Each interview is broken down into 'meaning units'; sections of data that contain important ideas. Each meaning unit will then be 'decontextualized' using an open coding process (Bengtsson, 2016). 5. Each category is grouped into a pattern. 6. Patterns are then further grouped into key themes. 	<ol style="list-style-type: none"> 1. Identified codes, data and patterns are interpreted.
Outcome	All interviews annotated using a colour-coded system, identifying ideas and concepts via both inductive and deductive reasoning processes.	Eleven key patterns are identified under three key themes (knowledge, attitude, and feeling).	A data analysis report is produced.

Researcher reflexivity was facilitated by maintenance of a reflective diary of methodological decisions and reasoning for discussion in supervision. Finally efforts were made to seek participant validation of findings via email communication of a summary of the eleven key themes identified. This process of data analysis is summarised in Table 2.

Context of research

Within the trust in which this research was undertaken, since 2005, only 42 families have been approached and asked to consider DCD donation, with twelve (28.6%) consenting and seven (16.7%) proceeding to donation (trust statistics obtained from SN-OD records).

Findings and discussion

Analysis generated eleven themes, which were categorised in line with the pre-defined deductive domains of: nurse knowledge, attitudes and feeling (Table 3). Themes were then identified as barriers and facilitators to DCD. As is usual in qualitative research the findings and linked discussion of findings will be integrated (Langridge and Hagger Johnson, 2009) supported by participant quotes.

Nurse knowledge and understanding of DCD POD

Knowledge deficits, limited access to educational resources, uncertainty around the role of the multi-disciplinary team (MDT) and a general lack of confidence were identified as barriers under the knowledge domain.

Table 3
Categories and themes developed from analysis.

Categories	Themes	Barriers or facilitators to the DCD process
Knowledge	Knowledge deficits	Barrier
	Perceived limited access to education	Barrier
Attitudes	Uncertainty about the role of the MDT	Barrier
	Lack of confidence	Barrier
Feelings	Positive attitudes	Facilitator
	Pre-conceptions	Barrier
Feelings	Impact of professionals beliefs and attitudes	Barrier/Facilitator
	Missed opportunities	Barrier
Feelings	Lack of public awareness	Barrier
	Nurse-family relationships	Facilitator
Feelings	Sensitivity of DCD discussions with families	Facilitator

Data analysis indicated knowledge deficit amongst participants, irrespective of length of experience, specifically when describing the donation process. There was a reported lack of DCD education and experience of the process amongst nurses.

Only two participants had direct experience of caring for a patient undergoing DCD, both senior Band 6 nurses with over ten years of experience. The infrequency of DCD is a reported barrier to learning, with three participants expressing the importance of learning from experience, to encourage confidence and develop necessary skills. This is supported by statistics that indicate that between 2005 and 2017, only 7 DCD cases occurred within the trust.

"Because we don't do it (DCD) much (it can prove difficult)... If we did it more we could make it more of a positive thing" (OD1:6(146–147)).

Only one participant reported formal training from Specialist Nurses in Organ Donation (SN-ODs) with four participants reporting that they had received informal guidance in response to specific questions.

Six participants (two of which have had first hand DCD experience) indicated that they would rely upon support from senior nurses to undertake the DCD process. However, senior staff themselves highlighted a lack of confidence and knowledge and questioned their ability to effectively support junior staff.

Participants spoke of a lack of understanding of the responsibilities of each member of the multi-disciplinary team (MDT) within the DCD process. For example, three participants in the study inaccurately reported that only the medical team has the appropriate training to identify potential donors. One participant incorrectly stated that SN-ODs identified potential donors by accessing patient notes. However four participants correctly indicated that the bedside nurse, alongside any member of the MDT involved in a patient's care, play a key role in identifying potential donors. In addition, all participants raised the importance of the wider MDT in supporting the family through DCD, including through family liaison, psychology and chaplaincy services.

Importantly participants highlighted three key roles of the bedside nurse in DCD and these were: acting as an advocate for the patient and family (liaising with the wider MDT), family support and providing comfort care for the child. However participants did not include referral of potential donors to the SN-ODs as part of their role (despite NICE guidance to this effect) (NICE, 2011).

The importance of the SN-OD was reported by participants, however, two participants had never met the SN-OD team and only three participants had had direct contact with the SN-OD team.

There was a feeling that SN-ODs were an important support and educational resource, but that they were not seen on the unit.

“The SN-OD is more experienced... That is their role... They are present and that (family support) is what we should use them for” (OD4:4(73-74)).

“The SN-OD needs to be called in more often. We don’t have much to do with them really” (OD8:5(47-49)).

“I don’t think SN-ODs are present enough on the unit” (OD1:6(111)).

As the UK literature identifies the SN-OD as essential to the organ donation process, as they play a central role in supporting families and PICU staff (Fenner and Gardiner, 2014) by drawing on skills and experience in dealing with acute grief and adopting appropriate and sensitive approaches to discussions (Garside and Garside, 2010), it is of concern that the reported perception of participants is that SN-ODs are not easily available to them as a resource. As consent rates are higher when a SN-OD is present in the request process it is essential that HCPs not know the referral process but also feel that they can contact SN-ODs as an education resource (ODTC, 2018).

In seeking participants views on what they felt they needed to be better prepared and confident in facilitating donation conversations, participants indicated that their preferred educational and support interventions would include: annual updates from SN-ODs, written guidance (source unspecified) and scenario-based simulation sessions provided by the trust. Participants indicated that this education should include information on the process of DCD donation, resources available for families, typical questions they may ask and how best to respond to these in association with greater SN-OD presence on the unit for provision of education and support.

In summary, a lack of knowledge leading to low confidence levels aligned with limited understanding of professional responsibility within the DCD process will impact on the identification and referral of potential donors and conversations with family members, all factors that have been evidenced as reducing the potential for POD to take place (Stavel et al., 2011; Weiss et al., 2016). The impact of grief, processing feelings regarding loss and comprehending death, can affect families’ ability to make informed decisions regarding donation and therefore having expert support and guidance is an evidenced facilitator to parental decision making (Christ et al., 2003).

Nurse attitudes toward DCD POD

Preconceptions of parental views acted as a barrier to POD under the attitude domain, with positive attitudes and professional beliefs working as both barrier and facilitator.

In line with the international literature the majority of participants stated that DCD should be offered to all suitable candidates (Curley et al., 2007; Kurz, 2014; Mathur et al., 2008; Stavel et al., 2011; Weiss et al., 2016). However, as reported by Ingram et al (2002) who surveyed critical care nurses in the USA, positive attitudes do not necessarily lead to action. In their survey of the majority of nurses had overwhelmingly positive attitudes toward organ donation, they failed to act on their beliefs. However, three participants raised concerns that patients are often not referred to the SN-ODs for consideration of eligibility, or offered the opportunity to donate due to staff assuming that parents in particular will hold negative views about POD.

“It’s hard to judge whether a family will be open to it or not... It’s definitely worth asking as they can only say no” (OD6:2(136-137)).

An admittedly small amount of international, empirical research is available reporting that parents are potentially more positive about donation than the relatives of adult donors with reasons for agreeing to donation including: compassion towards children waiting for transplants, the notion of reciprocity, believing it is the ‘right thing to do’ and believing the act of donating would allow their child to live on in others (Sque et al., 2003). Despite this evidence base, as reported here and elsewhere, health professionals working in this area maintain that paediatric and adult decision makers differ in significant ways. Therefore, a major barrier to meeting the demand for paediatric donation appears to be located first and foremost in the attitudes and behaviours of the health care providers who care for potential paediatric donors suggesting that these attitudes (and resultant behaviours) are likely to impact on the willingness to identify, refer, and approach potential paediatric donors.

Personal and professional attitudes were predominantly supportive of donation with three respondents reporting that they were registered organ donors. Positive attitudes to DCD have been reported as increasing the likelihood of nurses referring potential donors to organ donation services (Ingram et al., 2002).

Of note is that six nurses indicated their support for conscientious objection to nurse participation in DCD.

“They should be able to conscientiously object... perhaps they have had a relative pass away very recently and had to go through the same process... it might be very stressful” (OD4:4 (152-154)).

It was indicated that nurses were concerned regarding personal, emotional impact and the potential for their own views to influence the care that their patients and families receive. Shaw et al. (2018), highlights objection to facilitate organ donation is predominantly due to moral or religious objection, belief that it is against the best interest for the patient, that it causes burden on staff and that it causes an unfair distribution of resources considering the current demand for healthcare.

From a professional perspective all eight participants were of the unanimous opinion that the Nursing and Midwifery Council (NMC) code and professional responsibilities should inform their own opinions and attitudes towards DCD. For example the NMC code of conduct (NMC, 2015), states that it is essential that nurses “avoid making assumptions and recognise diversity and individual choice” (Section 1.3).

“You can’t be like well actually I’m not getting involved with that. You can’t pick and choose what your role is as a nurse... that’s part of what you sign up for... this is still providing care for your patient, which is ultimately what we are there for” (OD3:3(174-178)).

“It shouldn’t impact on the care that they receive; the care should be the same for everybody, and we have a duty of care, especially under the NMC” (OD4:4(147-149)).

However, four participants stated that although personal beliefs should not affect care provided, it may impact the donation process as if negative these views may reduce the potential of potential donors being identified.

“If opinions (held by self) might influence discussion, I think you should remove yourself from it” (OD5:8(165-166)).

In summary, despite apparent positive attitudes, concern over family wellbeing and stigma surrounding initiating these difficult conversations acts as a barrier to DCD facilitation.

Nurse feelings as barriers to DCD

Missed opportunities and a perceived lack of public awareness were the barriers identified under the feelings domain, with the

quality of nurse-family relationships being the facilitator identified.

Missed opportunities to identify potential donors and/or to refer potential donors to the SN-OD team were attributed to feelings that discussing DCD POD is ‘taboo’ a topic that should not be considered as part of end of life care. Participants indicated that such discussions may be perceived by family member to be inappropriate or demonstrate insensitivity at a time of family grief. Such feelings act as barriers to POD.

“There’s a taboo and stigma around whether, well, if we should have this conversation. It’s going to be a negative experience for the family” (OD1:6(144-146)).

Five participants highlighted their concerns when initiating discussions of donation with families due to a fear of causing distress.

“(It’s) such a sensitive subject. I wouldn’t know how to raise it. I wouldn’t personally raise it... parents become hostile about it” (OD3:3(144-148)).

Further to this, participants highlighted concerns that raising the issue of DCD may be inappropriate during a time of grief and heightened stress as the DCD process itself is time-sensitive, with retrieval of organs needing to occur within 240 min of cessation of heartbeat following withdrawal of life sustaining treatment (BTS, 2010). As empirical research has identified the importance of detailed and timely donation discussions with families positively contributing to consent rates (Rodrigue et al., 2008) the feeling that there is not enough time for staff to be confident that family members are fully informed and prepared for donation may be acting as a barrier to DCD being considered by health care professionals.

Furthermore the evidenced recommendation that discussions about the intention to withdraw life-sustaining treatment should be separate from any discussion regarding donation which includes a SN-OD (Brierley and Larcher, 2011) was felt to be a practical barrier to DCD by two participants, however another view was that DCD was not considered as a usual part of preparing family member for withdrawal of life sustaining treatment.

“It’s really hard with the nature of our unit, in particular, to call the SN-OD because of where we go with the patients... They don’t become candidates for organ donation anyway because (pause) they’re too sick” (OD8:5(31-32)).

“We don’t talk to parents enough about it, and as a step towards palliative care (or) withdrawal of treatment, I don’t think we bring it up particularly well or soon enough” (OD8:5(41-42)).

A key facilitator to DCD discussions was felt by participants to be a strong and trusting nurse-family relationship as this was perceived as pivotal to supporting families through the DCD process.

“It depends on your relationship with the family as to whether they [the family] would respond better [to DCD discussions] coming from you [the nurse] because they know you” (OD1:6 (76-77)).

“I think a lot of the time, they choose to have conversations with nurses that they feel comfortable with” (OD5:8(126-127)).

“If it were me personally, and it was a nurse I had worked with a lot, I would be much happier then having the conversation with me than someone that I didn’t really know ... I think it needs to be approached from a holistic, human point, not a clinical need for organs.”(OD1:6(128-131)).

UK data (Sque et al., 2003) discusses the role of rapport in donation situations. They underline the importance of family perceptions regarding quality of care, dignity and respect extended to the patient and the quality of communication as essential factors in facilitating organ and tissue donation discussions. Furthermore,

evidence reports that donation was more likely to occur if the family were approached about donation by a person they knew and trusted for example a member of the healthcare team such as the bedside nurse (Antommara and Bratton, 2008; Siebelink et al., 2011).

In view of the importance of relationships and trust it is essential that nurses feel able and prepared to support family members through the process of DCD, from approach to outcome.

Study limitations

The study sample included eight nurses from one PICU within one UK Trust and although this is small sample, the findings resonate with the small amount of literature that is available and so findings are transferable. All participants were female. We are unable to comment on why no males come forward for inclusion in this study (Males (5/100 account for 4.8% of Band 5/6 as of May 2017). Research was undertaken in the researcher’s place of work and this may have influenced participants’ responses.

Conclusion

This research has generated new insights into the knowledge, attitudes and feelings towards organ donation after circulatory death within one paediatric intensive care setting. It suggests that providing nurses with a platform from which perceived barriers can be discussed can have a realistic impact upon policies and practice changes, to better design the DCD process.

There was evidence to support findings of previous studies that highlighted nurses’ concerns over feeling unprepared for their role in the DCD process. These included poor knowledge of DCD protocols, anxiety over approaching family members and supporting them through donation and communicating with families and other healthcare professionals to facilitate consent.

The study findings support the need for education in light of poor DCD knowledge and understanding, and recommends the provision of specific educational interventions, appropriate resources and the development of paediatric-focused policy to guide practice.

Findings reinforce the important supportive and educational role that SN-ODs play and therefore service improvement initiatives must look to how they can be more ‘present’ on PICU units as a means of supporting DCD in particular. In view of the findings from completed research highlighting the impact of timely and appropriate family discussions regarding DCD, aided by strong and trusting nurse-family relationships and sensitivity of discussions as being fundamental requirements in paediatric donation proceeding, it is essential that PICU team development initiatives combined with improved public awareness are a focus for development.

This comes as government explores a move towards an ‘opt-out’ system for organ donation (DoH, 2017) as a potential solution to overcoming the shortage of transplantable organs and tissues. Despite these laws not including children under the age of 18, NHSBT is launching a paediatric strategy aimed at giving parents more chance to donate and improved support throughout the process (NHSBT, 2019).

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Conflicts of interest

Employment of primary researcher within trust in which research was undertaken.

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Not applicable.

Ethical approval

The study was approved by the University of Southampton's Ethics and Research Governance Committee (ERGO submission ID: 22998), NHS Health Research Authority, Clinical Research Adoptions Committee (IRAS ID: 216356/REC ID: IG/HRA/5736) and the local trust's Research and Development Committee (CRAC/R&D ID: 16HC25).

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.iccn.2019.07.004>.

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