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ABSTRACT

Background: Donation after Cardiac Death (DCD) is one possible solution to the world wide organ shortage. Intensive care physicians are central to DCD becoming successful since they are responsible for making the clinical judgements and decisions associated with DCD. Yet international evidence shows health care professionals have not embraced DCD and are often reluctant to consider it as an option for patients.

Purpose: To explore intensive care physicians' clinical judgements when selecting a suitable DCD candidate.

Methods: Using interpretative exploratory methods six intensive care physicians were interviewed from three hospital sites in Australia. Following verbatim transcription, data was subjected to thematic analysis.

Findings: Three distinct themes emerged. Reducing harm and increasing benefit was a major focus of intensive care physicians during determination of DCD. There was an acceptance of DCD if there was clear evidence that donation was what the patient and family wanted. Characteristics of a defensible decision reflected the characteristics of sequencing, separation and isolation, timing, consensus and collaboration, trust and communication to ensure that judgements were robust and defensible. The final theme revealed the importance of minimising uncertainty and discomfort when predicting length of survival following withdrawal of life-sustaining treatment.

Conclusion: DCD decisions are made within an environment of uncertainty due to the imprecision associated with predicting time of death. Lack of certainty contributed to the cautious and collaborative strategies used by intensive care physicians when dealing with patients, family members and colleagues around end-of-life decisions, initiation of withdrawal of life-sustaining treatment and the discussion about DCD. This study recommends that nationally consistent policies are urgently needed to increase the degree of certainty for intensive care staff concerning the DCD processes.

INTRODUCTION

In Australia organ transplantation is a well-established clinical practice and it is supported by the Australian Community. Organ transplantation is now considered a desirable treatment for many diseases, which affect organ function¹. Donation after Cardiac Death (DCD) is a possible solution to the world wide organ shortage². However, it was largely abandoned in the 1980's once the neurological certification of death could be legally used to declare death³. DCD has been re-introduced in many countries, including Australia, because of improved perfusion techniques which have led to better transplant outcomes⁴. Recent studies have found that health care professionals have not embraced DCD and are reluctant to consider DCD as an option for patients^{2, 5-7}.

There is evidence that health professionals are uncomfortable with the lack of standards for mortality prognostication and cardiopulmonary death. Moreover there is a perception that a perceived conflict of interest concerning priorities of goals of care exists between the junction of end-of-life care and the transition to implementing DCD procedures⁶. Intensive care physicians are also apprehensive when performing clinical assessments that involve a prognosis of mortality and making a clinical judgement determining whether a patient could be a suitable DCD donor⁸. Mortality prognostication and the associated requirement for an intensive care physician to predict survival times (to prevent prolonged warm ischaemia) following withdrawal of life sustaining treatments (WLST) have created uncertainty and trepidation for intensive care physicians^[8-11]. It has been shown that uncertainty about prognostication is due the wide variation in futility assessments and practice surrounding WLST which precedes DCD⁹⁻¹⁷.

Decision-making around end-of-life care in critical care has been studied extensively¹⁴ although, the complexities of how intensive care physicians make their judgements prior to initiating end-of-life care is not well understood. Current research associated with DCD has focused primarily on ethical concerns and clinical objective variables in the international setting^{4, 6, 18-21}. This paper reports the findings of a small exploratory study which sought to identify the tensions and complexities experienced by intensive care physicians when assessing and identifying potential DCD candidates in Australia.

METHODS

An interpretative exploratory approach was used to make sense of people's experiences within their own environment. This approach is useful to discover in-depth explanations from the perspective of participants when involved in prognostic decision making for the purpose of determining mortality and survival times necessary for DCD candidate selection²².

Network sampling technique was used to recruit participants from three hospitals in New South Wales, Australia. This sampling method allows researchers to access populations that are not easily identifiable or are small in number. Furthermore, this sampling technique is used when eligible people are known to the researcher and participants can involve other participants known to them who are interested and eligible²². All participants were members of the Faculty of Intensive Care Medicine and were recruited through an email invitation distributed by the Director of the Intensive Care Department or through the New South Wales (NSW) Organ Donation Intensive Care Physician Liaison committee. In exploratory qualitative research, the sample size is not pre-determined, rather data collection continues until saturation of themes is achieved²³.

Data was collected through semi-structured interviews with questions developed from the experiential knowledge of the authors and current literature (see table 1). Participants were encouraged to expand on their responses by using additional probing questions such as "can you please tell me more about..." and "what do you mean by..." Interviews lasted 60-90 minutes and were conducted in person at a location determined by the participant or over the telephone. Only minimal participant characteristics were obtained during data collection as: 1) it was not relevant for this type of study, 2) it contributes to protecting participant anonymity, and 3) all ethics committees agreed that other demographic details did not add value to the study. Interviews were transcribed verbatim.

Table 1: Interview Questions

1. Could you tell me the number of patient assessments for potential Donation after Cardiac Death you have undertaken?
2. Could you describe how you make a prognosis of mortality in an intensive care patient?
3. Could you describe how you determine patient survival time following withdrawal of life sustaining treatment?
4. Please describe the NSW criteria for selecting of Donation after Cardiac Death candidate.
5. Could you please explain how you select a candidate for DCD?
6. Please tell me about your experiences of identifying a candidate for DCD.
7. Which elements of the criteria are
 - i) easier to assess and why;
 - ii) more problematic to assess and why?
8. Are there any aspects of identifying a DCD donor that you find confronting or inhibiting?
9. What have you learnt about or developed in your practice related to:
 - i) candidate selection;
 - ii) withdrawal of life-sustaining treatment; and
 - iii) DCD process?

Verbatim transcripts were then subjected to thematic analysis using inductive techniques²¹. Thematic analysis involves searching through the data to identify recurrent patterns. A recurrent pattern then becomes a theme. The first analytical step involves coding each transcript line-by-line to develop first level codes. Subsequent steps involved grouping the initial codes into higher order common categories and then into final interpretive themes. These later steps were conducted by both authors independently. Discussion between the authors then occurred around the proposed theme. Through an exhaustive process of analysis and comparison back to the original transcripts, data were arranged in themes. These themes were then evaluated for the most appropriate fit with the original data (i.e. rigor). Saturation became evident as no new themes emerged. Finally one of the participants was invited to review the themes (i.e. confirmability).

Both hospital and university ethics approval was obtained at all sites from where participants were recruited. All participants were provided with an information statement prior to providing written consent. Each participant also had the option to withdraw consent at any time. All intensive care physicians approached agreed to participate (i.e. no-one refused) and neither did any participants subsequently withdraw. Interview transcripts were de-identified with numbers replacing participants' names.

FINDINGS

Six intensive care physicians (5 males) were interviewed from three different hospital sites. All participants were qualified intensive care specialists who had, at the time of recruitment, performed between two and fifteen DCD candidate selections. Participants described having been involved in as little as 30 or "too many to count" end-of-life judgments.

Thematic analysis revealed three distinct themes: i) reducing harm and increasing benefit; ii) characteristics of a defensible decision; and iii) minimising uncertainty and discomfort.

Reducing harm and increasing benefit

The first theme revealed how increasing benefit to the patient and their families was extremely important and a major focus for the participants in this study. If any treatment decisions led to harm for dying patients, participants felt it was ethically wrong to proceed with discussions concerning DCD. Accordingly, it was important for participants to create a benefit, (e.g. initiate palliation and reduce suffering through undesired active treatment) for the patient and family. Participants felt it was essential to identify when active treatment was no longer curative and ongoing treatment became a burden to the patient. This was expressed by participant one as:

"...people go from being salvageable to being unsalvageable and that you begin to recognise when the person is no longer just very sick but is in fact is actively dying and that once they move from that and into the face of being inevitably dying that I feel quite comfortable that I have reached the limit of my ability to make this person better,"

There were different factors which participants considered important to determining when active treatment became harmful. These factors were: recognising when all reasonable treatment options had been exhausted; that death was likely; active treatment was inappropriate; and presence of co-morbid conditions. Once it was clear that there was no further benefit of active treatment for a patient and death was probable, participants felt it was appropriate to consider DCD as an end-of-life care opportunity. The opportunity of DCD might then provide a benefit to patients and their families and then this became the goal of care. When discussing donation with a family, Participant Six stated:

“Organ donation is like all the other things that we do in trying to empower patients and their families, and if you don’t bring up organ donation then you are denying people that opportunity and that may be a bad thing to do for everybody”

Despite the possible benefits of DCD, participants were extremely conscious that an imprecise and uncertain DCD process could be harmful due to a protracted and lengthened dying process. Participant six described:

“... it [donation surgery] was going to be 10 o’clock and they couldn’t get in the operating theatre and then an emergency came in and then there was a caesarean. It ended up being one in the morning and the family are starting to think this is bloody torture, and ... and you’re not sure if they’re going to die. Then you get them down there at 2 in the morning, and they don’t die, and then you bring them back to ICU, that’s bad.”

Characteristics of a defensible decision

Theme two revealed intensive care physicians commonly made important clinical judgements regarding treatments and care of the patient. Participants described judging end-of-life, including DCD, as difficult, emotional and required careful consideration. They identified characteristics that safeguarded the wellbeing of patients and themselves. These characteristics helped participants to feel less vulnerable and open to recourse, and that their judgement was robust, justifiable and appropriate. These characteristics were: separation and isolation, sequencing, timing, consensus and collaboration, trust, and communication. If at least one of these characteristics were missing, participants were more likely to feel vulnerable and less able to embark on the subsequent DCD discussion and assessment with patients and families.

Participants identified that multiple decisions were required to WLST prior to DCD, and each decision should be made *separately* in *isolation* from each other, and in the correct *sequence*. Participants identified a potential for conflict of interest, concerning the correct goal of care, if the correct sequence, isolation and separation from previous clinical judgements were not achieved. Progression towards DCD was often dependent on the outcomes and characteristics of previous end of life decisions. For example, there must be an unequivocal judgement that a patient has no hope of a survivable outcome and WLST is appropriate before a patient can be considered a suitable DCD candidate.

Participants were concerned that there may be a perception, from other clinicians and family, that end-of-life care decisions, including WLST were initiated for the exclusive purpose of obtaining a DCD candidate. All participants described allowing sufficient *timing* between clinical judgments of WLST and DCD in order to minimise conflict of interests and confusion in the goal of care. More time, according to the participants, would (in most cases) allow the family to accept the prognosis of inevitable mortality before moving to the next discussions concerning end-of-life care. Participant Five stated:

“.....you may be actually trying to slow things down a bit, hang on a tick, that’s very nice and I hear what you’re saying and that’s very important and at this point in time, we are doing everything we can to try to get him better Um so, sometimes at least when the family raises that [donation] the first thing you need to do is acknowledge that but slow [and reorganise] it down a bit.”

Moreover, to reduce the risk of a conflict of interest, participants sought *consensus and collaboration*. This involved collecting information from other medical staff, the family, and the patient (advanced care directives or other documents – if available). Participant four described it as:

“...you have discussions with other medical teams looking after the patient as well as the family and the process of withdrawing includes gathering information about the patients current illness and their co morbidities before they became unwell, the

likelihood that they will survive whatever their problems were, and then getting an idea of family, as to what they would wish to be done and liaising with the medical teams. So that whole process takes a while, that can take days. So that's leading up to withdrawal. And generally we only do it if we've got medical consensus."

Additionally *trust* between all of those involved in making clinical judgements regarding end-of-life care and DCD was crucial. If there was a reduction in trust, whether actual or perceived, between a patient's family members and the participant, DCD assessment was unsuccessful. If trust was absent; other aspects of treatment may be questioned, for example, whether the correct clinical diagnosis and prognosis of mortality was made. Furthermore *communication* must be consistent for trust to be formed. Participant two described trust as:

"I think that they [family members] normally believe you. ... I don't think that they are mistrusting. Families, with time they trust and have a relationship based on trust with you. I think that if you do not confuse the families [with inconsistent communication] and if you are honest and transparent then there is no reason why there should be a conflict there"

Minimising uncertainty and discomfort

The final theme revealed the importance of decreasing the degree of uncertainty and discomfort for patients, their families as well as themselves and other intensive care physicians. To predict end of life, participants detailed the primary physical assessments they performed to increase the accuracy of prediction of length of survival following WLST. The assessments included respiratory assessments (i.e. assessment of breathing patterns, use of respiratory accessory muscles, apnoea tests, levels of oxygen and ventilator support, and degree of spontaneous respiratory effort), neurological assessment (level of consciousness) and the presence of cardiovascular instability requiring support. Participants also described the need for high levels of clinical experience and confidence when performing an assessment of whether the survival time would be longer than one hour (a patient must die within to hour following WLST for donation surgery to occur) so that unnecessary or ineffective assessments were avoided prior to recommending a suitable DCD candidate. Participant five explained:

"To be quite frank with you that is one of the most difficult areas in this entire DCD scenario, I personally am a little bit concerned about the 60 minutes cut off period, because there is no way even with my degree of knowledge after this number of years in critical care medicine that one could with any certainty predict that the patient will actually die within 60 minutes."

Discomfort was present for all participants when there was uncertainty during end-of-life decision making because there could be inconsistency between colleagues. Futility was often cited as a reason for WLST but was not well defined; what was futile for one patient was not always futile for another. The inconsistency in futility decisions caused discomfort for participants because others (colleagues, families or potentially legal authorities) may have a different interpretation of what was futile. Participants described how consensus was a way to increase consistency and to eliminate the discomfort surrounding futility. Participant two expressed a common view:

"Well it's not just the national practices after cardiac death it is around withdrawal of treatment.... withdrawal of treatment is very different in hospitals in Australasia... very different and therefore there is no consistency between our hospital and [another hospital in NSW]; between our hospital and New Zealand; between our hospital and Western Australia. They're all different. So we completely lack consistency. That leaves us very much more open to question, doesn't it."

To eliminate uncertainty and to increase consensus and consistency, concerning WLST and DCD, participants expressed the desire for more legislation, policy and protocols. There was a perception that:

You only operate with all party agreement and all party agreement is like ... it can change awfully usually in the middle of the process and suddenly you don't have all party agreement and then you're in trouble."[Participant 2]

Another area of uncertainty for participants was the certification of death. Participants described uncertainty because of the varied time frames imposed to certify death when the patient became a DCD donor. A participant's discomfort would be reduced if consistent time frames were used in all death certifications concerning donation. Participant six stated that:

".. the real problem for me is that the 2, the 5 and the 10 minutes are focused on the certification of death, whereas, we have always certified death and we've never had any problems before, and we haven't needed anyone to tell us if it's 2, 5 or 10 minutes. The real problem with organ donation is what happens after they are dead, and it's a fact that if you are going to take their organs out immediately afterward then that is a problem, and we ought to deal with that."

DISCUSSION

This study provides insight into the experiences of Australian intensive care physicians making clinical judgements concerning prognosis of mortality and candidate selection for potential DCD donation. The findings suggest that reducing harm and increasing benefit to the patient and family were a motivating factor for engagement of the physicians to make decisions concerning mortality prognosis and DCD candidate suitability. Participants used processes to safeguard their decisions which made the outcomes defensible.

Reducing harm and increasing benefit for patients is the corner stone of healthcare. It is based within the ethical principle of beneficence whereby physicians have a moral obligation to promote the well-being of the patient and reduce pain and suffering¹. In this study mortality prognosis and DCD was based on the recognition that the patient was no longer benefiting from curative treatment and the burden of harm was greater. The obligation to prevent harm has also been reported in other end-of-life care studies conducted in Europe and Canada^{11, 15, 17} but none of these studies were in the context of DCD.

This study found that DCD decisions were made within an environment of uncertainty due to the imprecision associated with predicting survival (or time of death). This uncertainty leads to feelings of personal discomfort. According to Fisher and Ridley managing uncertainty is a prerequisite for practice in the intensive care²⁴. Beresford²⁵ categorised clinical uncertainty into three categories: conceptual uncertainty, technical or procedural uncertainty and personal uncertainty. This study found that conceptual and personal uncertainty existed because of the inability to apply likely theoretical understanding of survival time in the complex situation of DCD.

The participants in our study explained that once an end-of-life care pathway was decided upon, they could consider DCD as a possible benefit for the patient and their family, however a major mitigating factor was a prolonged dying process (because of delayed WLST necessary to arrange the DCD surgery and recipient allocation). This was considered to be burdensome for the patient and their family. Mandell et al also described the burden of prolonging the dying process and the possible harm in their national study regarding health care professional's attitudes to DCD⁶. Yet, according to Mandell et al intensive care physicians felt comfortable engaging in the DCD process when the patient's family initiated the possibility of DCD. Our study supports this earlier finding.

Furthermore, D'Alessandro et al found that if DCD discussions were initiated by a health care professional during end-of-life discussions, rather than by the patient and/or the family, this could be perceived as a conflict of interest⁸. It has also been reported that it is important to reduce the risk of conflict by separating the discussion regarding goals of end-of-life and DCD^{1, 2, 4}, and that the decision concerning WLST should occur prior to any discussions concerning DCD^{1, 2, 4}. In this study reducing risk of misunderstanding and conflicts of interest was achieved by sequencing, separating and isolating the discussions and judgments concerning end-of-life care and DCD. Bernat⁴ described the boundaries of DCD as essential to reducing confusion regarding the goals of care. The Australian National DCD Protocol also recommends that separation is essential to the success of the DCD process and candidate selection²⁶.

This is the first study to describe a process using the same person to maintain a trusting and consistent relationship when initiating discussions with the family regarding DCD. There is some disagreement in the literature, however, regarding whether it should be the same or a different person to initiate DCD discussions. For instance, other studies have recommended using a separate person to initiate DCD discussions in order to achieve separation and isolation^{6, 8, 19}. The Australian and New Zealand Intensive Care Society (ANZICS) statement on organ donation recommends a consistent approach, it does not,

however, encourage the introduction of unknown people who have not had the opportunity to develop a trusting relationship with the family²⁷. Interestingly, Billings agrees with our findings that trust and open and honest communication is crucial when discussing end-of-life with families. He also agrees that using another (new) physician in this circumstance should be avoided²⁸.

We also found that consensus and collaboration were important in the prognostication of mortality and DCD candidate suitability. No previous studies describe these characteristics as necessary for DCD discussion to proceed, although, guidelines and consensus statements exist for end-of-life discussions^{26, 29}.

Limitations

As an exploratory qualitative study, the findings focus on the local context and the particular time in which this study took place and while they are not generalisable to a wider population, the findings may resonate with other Australian intensive care physicians. Some of the participants had few experiences with DCD and this may have limited their understanding and insights into their experience. All participants, however, were routinely involved in mortality assessments.

CONCLUSION

This study expands the current knowledge of Australian intensive care physicians' judgement concerning a prognosis of mortality for the purpose of DCD. It demonstrated that physicians proceeded to discuss DCD if there was evidence that donation was what the patient and family wanted. Uncertainty about the possible harm to the patient or family, and the protracted DCD process created the most concerns. Until greater accuracy with predicting death becomes available, unambiguous and consistent policy across Australia is urgently required to decrease the degree of uncertainty for intensive care physicians.

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