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Donation after circulatory death - an expanded opportunity for donation appreciated by families



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1. Introduction

Until 2014 when controlled donation after circulatory death (cDCD) was reintroduced in Norway, it was only possible to fulfil the deceased's/family's desire for organ donation in cases where the lethal brain injury met the criteria for total cessation of brain circulation, donation after brain death (DBD). After reintroducing donation after circulatory death (DCD), many countries have focused on ethical concerns and issues regarding the criteria used to determine death and the need for guidelines [2,3,6,8,11,16,18,32]. Many healthcare professionals are concerned about how the next of kin experience DCD [4,10,16,24].

Most studies involving experiences around DCD are often limited to healthcare professionals [4,5,9,16,24]. Studies related to next of kin experiences are often limited to DBD [4,5,16,22,23,26,27,28] and more research on next of kin experiences with DCD is called for [6,12,17,18]. DCD can be performed both as uncontrolled (uDCD) and controlled (cDCD) with varying methods.

Two review articles found that the general public's support for DCD was somewhat less or the same as for DBD [16,24]. Several articles that examined healthcare professionals concern with DCD are linked to end-of-life care and decision-making round withdrawal of life support [13,14,16]. One article described the use of the Palliative Care Team and argued that the team made a significant contribution both to the patient and to the family in the organ donation process, especially with DCD [17]. The authors argued for further research and experience in this area, and that national discussions are being conducted to refine this practice that will benefit the bereaved families in a difficult and challenging process [17]. Two studies that argued for specific donor oriented skills in care for relatives as important, recommended that major studies should be conducted to investigate families' need and

their desire for support in the context of grief and donation, especially pertaining to the families who decline donation [21,29].

"The offer of organ donation should be a routine part of planning end of life" is one of the two main principles in the UK Donation Ethics Committees in its guidelines [19]. The Committee recommended that a specialist nurse in organ donation (SN-OD) should be notified, to support the donation process, every time a decision to withdraw treatment was agreed. In 2012, an official statement was made by a multi-disciplinary panel of stakeholders in US, "Ethical and policy considerations in organ donation after circulatory determination of death" [32]. The document contained recommendations on how to care for the relatives and recommended that hospitals should establish local DCD protocols and ensure that personnel with knowledge about palliative care were available and participating.

A study [31] that considered what information about DCD is possible to search for on the internet revealed a lack of information regarding DCD in organ donation webpages. The study recommended that more information about DCD should be made available to the public.

In this study, we aimed to provide insight into how donor families of cDCD donors experience the different phases of the donation process.

2. Materials and methods

2.1. Study design

An exploratory research design was chosen using in depth interviews as this approach facilitates knowledge, insight and understanding of the phenomena of being a close relative participating in a controlled DCD situation. The following research question was formulated: How do close relatives of cDCD donors experience the different phases of the donation process?

2.2. Clinical context

As the shortage of organs for transplantation increases, maximizing organ donation opportunities through cDCD has become an option at many transplant centres. Most commonly cDCD is realized in patients with irreversible brain injuries not meeting brain death criteria.

However, there is a lack of knowledge of the cDCD process, also as seen from the bereaved families' perspectives. Hence, we carried out a study to develop new knowledge within this area.

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2.3. The cDCD procedure

The cDCD protocol followed approximately the same procedure as described by Magliocca et al, 2005 at the University of Michigan [37]. Our protocol utilized normothermic regional perfusion (NRP) support of abdominal organs following death declared by permanent cardiac- and respiratory arrest. The protocol was reviewed by the hospital Ethics Committee, accepted by the Regional Ethical Research Committee and supported by Oslo University Hospital, Division of Emergencies and Critical Care. Inclusion criteria for protocol eligibility were patients in a coma with documented severe irreversible neurologic injury, age 16 to 60 years and on mechanical ventilation. Patients who were unlikely to meet the criteria for brain death and with families that had accepted withdrawal of life-sustaining treatment (WLST) were identified as potential cDCD organ donors. These patients were referred to the national organ procurement organization. If a patient was deemed to be medically suitable, the family was offered the opportunity to pursue organ donation after circulatory death. After consent for donation was granted, the NRP team was notified and a central line was placed in the common femoral artery and vein. 5000 IU Heparin® was given iv. pre-mortem and before WLST. Preparatory cannulation for NRP took place at the bedside in the ICU but without initiation of perfusion before declaration of death.

All pre-mortem patient management was conducted by the primary service, whom were not affiliated with the organ donation service. At the next of kin request and after a minute of silence, life support was withdrawn and comfort measures continued, in the ICU. Upon their wish the next of kin could be present, bedside during the WLST. If circulatory death did not occur within 60 minutes, the patient was no longer considered a candidate for cDCD. After cardiac and respiratory arrest, and a further 5-minute observation- and “no-touch” period, the primary medical physician made the declaration of death. The next of kin had agreed to leave the room after the 5-minute observation period.

Using percutaneous Seldingers technic, cannulas were placed after the declaration of death to accommodate the NRP circuit and provide an organ preservation flush line. To avoid cardiac reanimation the thoracic aorta was occluded with a balloon catheter inflated with radiopaque contrast material. Correct placement was confirmed by chest x-ray. The next of kin were then welcomed back to the room before the deceased was transported to the operating theatre.

2.4. Study sample

The participating informants, being close relatives to patients with acute irreversible brain injury, were recruited from one university hospital in Norway on the spot approach by the responsible physician. At the same time as the family received oral and written information concerning the cDCD study, and gave their consent to organ donation, they agreed in writing to participate in the study. All potential informants being invited accepted. 15 informants representing seven donor families, and being a close relative in a cDCD situation, were interviewed in depth (Table 1). The informants were between 18 and 70 years, representing a broad variation in age. In total families of eight cDCD-donations were asked to participate. However, for reasons not known, one family did not want to participate. Inclusion criteria

were being a close family member of the cDCD-donor, having consented to cDCD organ donation, having been present during the donation process, being aged 18 years or older, and willing to participate.

2.5. Data collection

Two researchers carried out seven in-depth interviews in the period July 2014 and February 2016, taking place between 2 and 6 months after fulfilled donation. The interviews, which were audiotaped, were conducted using a semi-structured interview guide (Table 2) and lasted approximately 60 min ± 20 min. They were carried out in a room where the interview could take place without interruption. The room had a relaxed atmosphere containing comfortable chairs and a table with water, soft drinks and tissues. All interviews began with a short briefing about the purpose of the study. During the interview, the researcher asked follow-up questions, so the informants had to further elaborate on the statements they had made. Probes were used to stimulate narration, such as “What did you think then?” After the interview, participants were given the opportunity to ask questions and seek clarification if they felt anything was left unclear.

2.6. Data analysis

All interviews were transcribed verbatim and analysed according to Kvale and Brinkman's 5 steps of meaning condensation [38]. Step 1 was to read all the transcribed text to get an overall impression. During Step 2, the transcribed text was perused in more detail, looking for meaning units in the interviews. The text gave an impression of what the participant meant by saying what he or she did. During Step 3, we formulated and categorized the themes dominating a meaningful unit and tried to state these as simply as possible into subcategories. The aim of Step 4 was to consider if the main themes answered the research question. Step 5 aimed to tie the main themes into a descriptive statement. An example of the data analysis process is shown in Table 3.

To enhance validity Kvale and Brinkman's description of the validating process was followed [38]. The researchers read the transcripts separately, and subsequently met regularly to assure an accurate reflection of the interview data. Alternative ways of interpreting the data were discussed carefully until a consensus was established between the researchers.

2.7. Ethical considerations

All participants were informed about the study both orally and in writing. They were assured that they had the right at any time to discontinue their participation and that the collected data would be handled in a confidential way to be used only for the declared purpose. The hospital provided a backup contact (dialog with a psychiatrist) for the participants following the in depth interview. Nobody expressed a need for this backup contact. The study was approved by the Norwegian Regional Committee for Medical and health Research Ethics (#1.2008.832).

Table 1
Characteristics of informants and donors.

Interviews	Relationship to the deceased	Length of time bereaved (mo)	Donor age/sex	Critical illness/injury
1	Stepmother	3	35 - male	Head injury
2	Wife and daughter	2	60 - male	Brain haemorrhage
3	Wife and daughter	6	52 - male	Cardiac arrest
4	Wife and two daughters	4	58 - male	Head injury
5	Mother, father and sister	2	42 - male	Cardiac arrest
6	Wife, son and daughter	2	47 - male	Head injury
7	Partner, female	4	34 - male	Cardiac arrest

Table 2
Interview guide.

	Topics covered in interviews
Before decision to donate	What was your experience of the information given from healthcare professionals about the possibility of cDCD? How was the new method explained? How did you comprehend the criteria of death and cDCD? What was your reactions and reconciliation to the situation? How did you experience the attitude, communication and support from healthcare professionals?
The decision	How did you experience the process of consenting to cDCD? What are in your opinion the pro and con arguments for consenting to cDCD? Did you experience ambivalence, worries or strains? Were you provided with enough time? Did your family approve of your decision?
The donation process	How did you find the environmental conditions, such as facilities and the opportunity for peace and quiet/privacy? How did you experience the information and communication with healthcare professionals? What has been your experiences related to being together with the dying person, integrity and respect both for you and for the dying person, time provided for personal requirements and needs, the environmental conditions such as facilities and the opportunity for peace and quiet/privacy, shared decision making and the end of life care provided by healthcare professionals?
Time after donation	How did you experience the last ceremony? In your opinion were individual needs met? What reflections do you have on loss, reconciliation and acceptance? What reflections do you have on the donation contribution? What overall reflections do you have on the donation process?

3. Findings

3.1. Ambassador of the new cDCD method

The informants reflected a positive view on organ donation and they all supported cDCD as a method. None of the informants had previous experience with organ donation or knew the difference between DBD and DCD/cDCD. The positive view of the informants was expressed in different ways: They were proud to take part in the study, and they also expressed pride on behalf of the organ donor to be part of this pioneering research. They expressed enthusiasm for the extra attention and support and they argued for establishing cDCD as an option for organ donation immediately. Some claimed that cDCD is a better alternative than DBD, and others were grateful for the cDCD opportunity when the criteria for DBD are not met.

“X would have loved to be the first in Norway to take part in this research project” SC1

Several supported the view that this was a method that should be offered to everybody. Some also believed that the method should be established as an offer straight away.

“Why haven’t they done this before? Anyway, we find it strange – so why can’t they just do it like this?” SC4

Quite a few of the informants also felt that cDCD for them was the only option for donation, and that the method was a better choice than DBD. They were uncertain about supporting donation if DBD was the only option. The chain of cause for this conclusion differed among the donor families. Some families were first asked for DBD. A wife told us that she could not accept DBD since she could not go on living without being present when her husband ceased breathing. The visual experience of death was the crucial element for her. Without cDCD organ donation was not an option. The wife and both her daughters were supporters of organ donation. However, they never understood that this entailed that death would occur while the deceased was

connected to a ventilator – and that the treatment would be maintained until organ retrieval. Others argued that cDCD was the only option since they could not agree on DBD in the family. For others, it was all about not wanting to donate the heart.

“When the topic of organ donation was raised, I said, I remember saying, take everything except his heart, it was all OK by me, but I have this notion about the heart.... I just feel that the soul is in the heart. So, no matter what, not the heart”. SC7

Some were offered cDCD since the patient never reached the criteria for brain death, as required for DBD by the Norwegian legislation. The solution offered was well received among the families expressing relief and gratification for still being offered the opportunity for organ donation.

“If there is such a thing as a Holy Ghost, it was something like that which came to me – and I was literally just floating out of my car so to speak – it was just a huge Yes!”. SC5

3.2. Need for precise information and predictability

The findings showed that predictability and precise information was important for the next of kin in their situation. It prepared them for what was going to happen and contributed to building trust. Clear and unambiguous communication facilitated understanding of the information they were provided. They were also given the opportunity to express their own views and thoughts. The communications skills of the healthcare professionals when it came to dealing with people in acute grief, was also instrumental in creating confidence in the information they received, enabling them to let go of their own personal hope that the patient would somehow survive.

The interviews contained numerous statements where the informant pointed out information that made the situation predictable. Clear agreements about what was going to happen and when, as well as information about the preparations of the measures to be implemented – was appreciated. The preparation of the next of kin for

Table 3
Examples from the analysis process.

Meaning units	Subcategories	Main theme
“They have always been so clear in their information, and I guess that’s why we have been confident, I never really thought of doing things differently”. SC2	Direct and thorough information was highly appreciated.	Need for precise information and predictability
“Those who ask the first time, should be very clear about the two alternatives from the start”. SC4	Need of a clear structure and a detailed plan during the whole donation process.	
“It was good to know that, if there’s something that feels wrong during or when it happened, we can just end it”. SC4		
“They called to ask if we could come by tomorrow, because they wanted to talk with us. I then said that I wanted to come in today ... I could not have the night to think about what’s coming. So, we went to the hospital and met with the team that made the request concerning DCD. They gave a very thorough explanation about what was going to happen, and stuff”. SC5		

visible signs of the time of death, so that there would be no surprises, was highlighted as positive.

“And to have a plan for it, a clear plan and follow it, that I think will take you a long way.” SC2

In a setting where the patient was about to die, being prepared for the sad news and that the information was unambiguous and precise was appreciated. The fact that the doctor was direct and to the point was important to understand the graveness of the situation. The lethal injury was not always visible to the next of kin, and the dying patient just appeared to be sleeping. The informants described the direct information as devastating, but it helped them. The informants also disclosed that they wavered in their understanding of the situation, and that they needed to be told how to interpret their visual impressions. As for the conversation about organ donation, they would have preferred to receive the information about DBD and cDCD at the same time. The family members indicated that they would have preferred a competent person with knowledge of both DBD and cDCD to participate in the first conversation.

“Those who ask the first time, should be very clear about the two alternatives from the start”. SC4

The informants described that they had understood the difference between DBD and cDCD, and that with cDCD the heart and lungs could not be donated. The provided information contributed to building confidence.

“They have always been so clear in their information, and I guess that’s why we have been confident, I never really thought of doing things differently”. SC2

It derived from the interviews that the informants were thankful that the conversations about cDCD were facilitated and staged in an atmosphere of peace and quiet. The informants’ descriptions expressed a sense of recognition and respect. They indicated that they were given the opportunity to ask any question, enabling them to get the answers about the technical procedure and how long time the organ donation process will take. The information conveyed was facilitated and designed in a way that addressed the arguments of the informants, something that reflected mutual respect. This respect was also evident in the way the informants felt free to change their mind and withdraw if they felt that something was not right for them.

“It was good to know that, if there’s something that feels wrong during or when it happened, we can just end it”. SC4

We also identified informants who played a more proactive part when they were ready for more information, both by postponing or expediting the time for a talk.

“They called to ask if we could come by tomorrow, because they wanted to talk with us. I then said that I wanted to come in today... I could not have the night to think about what’s coming. So, we went to the hospital and met with the team that made the request concerning DCD. They gave a very thorough explanation about what was going to happen, and stuff”. SC5

3.3. Acceptance for the cDCD procedures and equipment used

The informants found the provided cDCD procedure information good and remembered being informed that donation was no longer an option if death did not occur within 60 min.

“If he lived for 65 min they couldn’t remove his organs” SC5

The families were informed that they had to leave the room 5 min after circulatory arrest had occurred. When they were informed that

the five minutes had passed, none of the informants found this problematic. As long as they were informed in advance, it was OK. Some described the minutes as tough and seemingly lasting forever. The minutes were also regarded as too brief to say properly goodbye for a minority. However, the informants understood that this was the way it had to be to make use of the organs. Some said that they did not need to stay any longer, because they had said goodbye for so long in advance.

“We were allowed in when they disconnected him from the ventilator. We were there until it all ended, and five minutes after that – then we had to leave. It didn’t matter that much, as I had been lying beside him for almost a week so to speak. It felt like a relief in a way, after waiting so long... for him to pass – the wait wasn’t exactly fun that either” SC7

For the majority, the most important thing was to be present when death occurred.

Some of the informants described the information given them regarding the technical procedures on the dying as complex – and some took no interest in understanding what was presented them – while others could convey a detailed understanding of the subject matter.

“I think we were informed properly. About the catheters that were placed in the groin, and the balloon that was inserted into the aorta, and about the order of things to be connected all the time – yes I think the information provided was very good”. SC2

The families could render a simple understanding of the purpose of the NRP machine.

“When the heart stops beating, a machine will be connected to circulate the lower parts of the body”. SC6

All the informants had understood that the NRP machine was an organ protecting measure after death had occurred. The informants described a natural transition from life to death. They did not find the covered machine and equipment that stood stand-by in the patient room intimidating. Some had noticed the equipment, while others had not.

“I didn’t see it, I don’t remember it. I can’t recall seeing it. I remember the nurse leading me out of the room, I was given a blanket, that’s all I remember”. SC3

The same applied to their experiences concerning leaving the patient room after five minutes. Some noticed the considerable number of healthcare professionals who were dressed sterile outside the room – while others had no recollection of this. Those who noticed described this only as a positive experience. Several informants said it made them proud to see so many involved in facilitating for the organ donation.

All the informants were offered to return to the deceased after the NRP machine was connected. The informants remembered seeing the machine in the room, but it was covered. None of the informants found this to be problematic, as all attention was centred around the deceased. The machine was unimportant because they knew their loved one was dead.

“When we returned and you had connected, there was a type of machine by the bed, but apart from that there was nothing, we couldn’t see anything of what was going on, and anyway – dad was dead.” SC4

3.4. Good – quality end of life care

The families appreciated that care for patients and their families at the end of life had priority before focusing on organ donation. According

to the informants, focus was directed at the persons involved – not the organs.

“I felt that he was – and we were the centre of attention, it was all about us, about dad dying. It was not about the other stuff (cDCD). That took second place”. SC4

WLST was highlighted as especially dignified since it was initiated with a minute's silence. Although there were several healthcare professionals in the room, the informants did not find this disturbing or even sense the presence of the staff. Others experienced the presence of professionals when death occurred as a comforting factor.

“We had peace and quiet around us. The staff were there but they weren't, they were quiet and we had the opportunity to concentrate, be together with him, be with him”. SC3

Farewell and WLST took place in the patient room at the intensive care unit. We identified that the informants experience dignity, professionalism and confidence in the final treatment and care of the patient. Most families reported being offered enough time to say goodbye. They appeared to have experienced clear agreements about time and schedule in close communication with staff.

“Then we entered the room and spent the time we needed. We got time for ourselves and were offered the time we needed. No one hurried us, it was quiet and calm”. SC6

The informants stated they were respected for the choices they made. Some did not want to be present when WLST. They expressed gratitude that someone was holding their loved one's hand when he died. The informants who were present when death occurred, appreciated being prepared in advance for what was going to happen when WLST, and that everything went as planned. They were warned that gasps could be heard from the dying. They expressed gratitude for the way the personnel focused on them as next of kin, and took their feelings into consideration.

Facilitation for the next of kin was also about having a place to be alone in the final stages.

“The last day we got a large room to ourselves away from xxx's room. This was something we had been missing the last few days, since the waiting room was always crowded”. SC7

Absence of pain was a key issue for the informants. They were concerned that the dying should not experience pain or suffering. A prerequisite for accepting organ donation in the first place, was that this would not inflict suffering for the patient.

“Most important for me, was that he wouldn't be suffering in any way”. SC7

4. Discussion

In this article, we have given an account of how the next of kin experienced the cDCD process. This paper adds new and valuable information to an area with little knowledge [1,2,12,15,21,31], even though DCD is not a new concept – but in fact the foundation of modern transplantation [1]. It is a key finding of ours that all informants were positive to cDCD. The next of kin found the method very meaningful, and for some it was the only option that made donation possible. The informants saw themselves as seen and well taken care of, and they conveyed a desire that the method be implemented on a regular basis. Our findings present new and significant information that will benefit both healthcare professionals and the community at large. When it comes to healthcare professionals our findings clearly demonstrates

the importance of thorough planning, warm, honest and direct communications with family members and the meeting of individual needs of the patients and the concerned relatives [34,35]. Concerning community at large our findings demonstrates that a well-planned cDCD donation represents an important alternative to the well established DBD.

Our informants expressed gratitude for organ donation. These findings are consistent with other studies that describe relatives' experience of organ donation as a positive event that comes out of a tragic death and loss of a family member [1,4,5,21]. Our study reveals surprising attitudes of the relatives, who described that they prefer cDCD to DBD. This strengthens the conviction that cDCD is an important service. Many studies argue to the contrary, that DBD is preferred to DCD [2,6,15,30], but Volk [33] supports our finding. Volk et al's informants highlighted the possibility of being present and to observe that the heart stopped and death occurred – something which is also described by Hoover et al [4]. Another reason may also lie in the emotional understanding of being dead when the deceased's heart continues to beat, as is the case with DBD [5,8,9,12].

The donation process and care of next of kin in these cDCD processes were carefully planned in distinct sequences. This strengthened the communication and formed a good basis for providing unambiguous and clear information to the relatives. Guidelines that later have emerged from the UK and the US support this procedure [19,32]. The donor family received a detailed description of the new cDCD method with implications for pre- and post-mortem interventions. The consequences for them, where their choices were emphasized both orally and in writing, were conveyed. This meant that the next of kin could prepare and establish confidence in both the healthcare professionals and the process about to start. Honesty and integrity in this information made the process more transparent and strengthened the families in the different phases of the donation process. The study therefore finds that the decision of cDCD is based on open and honest information communicated to the next of kin. Information that is unambiguous and precise, and contains detailed information about the donation process, made the situation predictable for the next of kin – something that was appreciated. An important finding of ours is that this communication worked well, even via interpreters. Trust is built when healthcare professionals show acknowledgement and respect, have knowledge about communicating with people in acute grief, and convey information in an unambiguous language/body language – in a quiet environment with ample time for questions. And finally, that the next of kin are granted time to realize that hope of survival for the patient is no longer realistic. The literature supports the importance of our findings [1,2,5,7,12,19–22,25,28,29].

The informants recounted both insight and understanding for the technical and the special aspect of cDCD. This included both pre- and post-mortem interventions, the consequence if death did not occur within 60 min, leaving the deceased five minutes after circulatory arrest, and execution of the donation procedures. It was reasonable to assume that the experiences associated with cDCD could be challenging for the relatives. On the contrary, the informants indicated that they were well prepared. They understood what was going to happen, and that the consequences of the donation procedures were acceptable for them, since they were prepared. In addition, the informants expressed the positive aspect of being so well taken care of by the personnel as the various procedures were carried out. They felt that their specific needs were observed and addressed also in this phase. We have no knowledge of previously published research on next of kin understanding of the donation process by cDCD using NRP. When trying out new methods, healthcare professionals may tend to foresee greater problems – often related to ethics – than the next of kin themselves experience. This was also evident when introducing cDCD in Norway. This underlines how important it is to allow the next of kin to have their say when a new treatment is to be evaluated [36].

Many of the informants' main priorities were that the dying/donor should not have to experience pain in any of the phases. Overby [2]

argues that adequate pain relief must be included in the DCD protocol to ensure a common standard in this area. Some argue for using designated palliative personnel with DCD to strengthen this specific function in the donation process [6,13,17]. In the UK, they are considering using SN-ODs to support organ donation, as a natural part of end of life planning [19,30].

All informants emphasized that the donor must be treated with dignity and respect, and they felt accommodated in this respect. Introducing a new method may result in focusing on the technical implementation, as opposed to focusing on the patient and next of kin. Our informants did not experience this. On the contrary, they reported that both the patient and the next of kin were treated with respect and dignity in the various phases of the donation. In this qualitative study of factors influencing the decision about organ donation and its impact on the family's grief, Hoover et al. describes how some families need to be present when death occurs, some to get evidence of a peaceful death [4]. WLST by cDCD in our study takes place at the ICU, and the next of kin were invited to be present throughout the process, when death occurs and until the NRP machine was connected. None of the informants claimed that they experienced unwanted or unexpected consequences of organ donation. Careful planning, good practices and attention to individual needs may have contributed to a process that was experienced as positive for the families.

The study's result is undoubtedly affected by the fact that it includes relatives in a particularly vulnerable situation. The study was performed on cDCDs from several intensive care units, but all in the same hospital. We acknowledge that the study represents only one of the country's hospitals. Therefore, there will still be a need to develop further knowledge about the bereaved families' experiences and needs in the cDCD process. A strength of this qualitative study is that as many as 15 next of kin participated and represented a broad variety concerning age. Thus, we consider the validity of this study to be satisfactory.

5. Conclusion

Our study brings novel knowledge concerning the introducing of cDCD as a new option of organ donation. The study revealed the importance of careful planning, good practices and attention to individual needs for both the patients and their families in the different stages of the donation process. Also our findings demonstrated an overall positive experience by the bereaved families.

Conflicts of interest statement

The authors declare no conflict of interests.

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