Potential donor families' experiences of organ and tissue donation–related communication, processes and outcomes

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Summary

We aimed to describe the experiences of families of potential organ and tissue donors eligible for donation after circulatory death or brain death. Forty-nine family members of potential donors from four Melbourne hospitals were interviewed to assess their experiences of communication, processes and the outcomes of donation. Interviews were recorded, transcribed verbatim and analysed thematically. Families expressed a range of perspectives on the themes of communication, hospital processes and care, the processes of consent and donation and reflected on decisions and outcomes. They expressed satisfaction overall with communication when receiving bad news, discussing death and donation. Honest and frank communication and being kept up-to-date and prepared for potential outcomes were important aspects for families, especially those of post circulatory death donors. Participants reported high levels of trust in healthcare professionals and satisfaction with the level of care received. Many donor families indicated the process was lengthy and stressful, but not significantly enough to adversely affect their satisfaction with the outcome. Both the decision itself and knowing others' lives had been saved provided them with consolation. No consenting families, and only some non-consenting families, regretted their decisions. Many expressed they would benefit from a follow-up opportunity to ask questions and clarify possible misunderstandings. Overall, while experiences varied, Australian families valued frank communication, trusted health professionals, were satisfied with the care their family member received and with donation processes, despite some apparent difficulties. Family satisfaction, infrequently assessed, is an important outcome and these findings may assist education for Australian organ donation professionals.

Key Words: organ donation, brain death, circulatory death, consent, donor family, intensive care

Organ and tissue ('organ') donation and transplantation rates have increased steadily in Australia since the 2009 Australian government's national reform. The initial focus of the reform included increasing the donor pool, mainly via the introduction of donation after circulatory death (DCD) in many Australian hospitals, and on improving donor recognition and referral. The number of organ donations and transplant recipients has increased by 58% and 39%, respectively, between 2009 and 2013[2].

More recently, the focus of the reforms has moved to improving rates of consent to organ donation. Family consent rates have remained around 60% between 2011 to 2013 for donation after brain death (DBD); potential donors[2–4] and consent rates may be lower for DCD potential donors[5], although national data are not available. International literature has sometimes described a reluctance from clinicians to request donation for fear of adding to family grief, or due to a lack of their own knowledge about donation[6]. Professional education workshops, which aim "to provide participants with the necessary knowledge and skills to sensitively support grieving families to make an informed, proactive decision about donation"[7], are mandatory for medical and nurse donation specialists working in the Australian DonateLife network and all intensive care medicine trainees in Australia. Our previous study has reported reasons for Australian families' organ donation decisions[8], however there are few reports available on how Australian families experience the request for consent or the organ donation process, and those available date from before the national reform in 2009. To our knowledge, the last published data on Australian families who decline consent was collected over 20 years ago[10]. Understanding potential donor families' experiences and reflections on processes may inform strategies to improve organ donation conversations and processes, and ultimately consent rates.

As part of a larger mixed-methods study assessing factors related to decisions and experiences of families of potential

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organ donors in Victoria, Australia, this manuscript reports the qualitative assessment of the experiences of the request for consent in both families who consented to donation and those who did not and, in those whose family member consented to donation, of the processes around donation.

Methods

The research team consisted of medical doctors, psychologists, researchers, donation specialists and a family support coordinator. Methods and results pertaining to the decision-making of families from this study have previously been described[8]. Approval was obtained from the Human Research Ethics Committees (Approval Nos.: H2012104607, HREC/12/MH/85, and D/019/12) of the four participating hospitals and all families provided written or verbal consent.

Participants

Potential organ donors were consecutively identified by donation specialists from four hospitals in Melbourne, Victoria, between April 2012 and September 2013. Following the collection of demographic and other data regarding the potential donor, family members who had been involved in conversations regarding organ donation were invited for inclusion in this qualitative study if they were English-speaking or could nominate an English-speaking spokesperson. Recruitment for consenting and non-consenting families was halted when the themes emerging from interview for that group were saturated.

Procedures

A personal letter, information detailing the study aims and methods and a consent form were sent to the next of kin recorded in the medical record six weeks following the death of the potential donor. This package included a stamped opt-out card to return if the family did not wish to be contacted. Families were contacted by telephone two weeks later to explain the study and request interview. Interviews were conducted face to face by two researchers, at a location convenient for the participants who were provided with taxi vouchers to compensate for travel, or by phone if there were time or distance constraints. The three interviewers had training and extensive experience in communication with bereaved families and had not been directly involved in clinical care of the deceased. Interviews were recorded and took between 30 and 90 minutes. Participants were encouraged to bring a support person to the interview and were offered a follow-up phone call or consultation with the family support coordinator.

Instruments

The interviews were semi-structured, with guides developed by the research team based on existing literature, and included questions regarding demographics and characteristics of the deceased's hospitalisation, and then open-ended questions to allow participants to describe their experiences regarding the hospitalisation and the death of their family member, their interaction with healthcare staff, conversations and knowledge of organ donation, and the

Table 1

Participant demographic details

	n	%
Age in years, average (SD)	*50.3*	*(11.2)*
Gender		
Female	32	65.3
Male	17	34.7
Relation to patient		
Partner	17	34.7
Daughter/son	16	32.7
Sibling	9	18.4
Parent	3	6.1
Family friend	1	2.0
Daughter-in-law	1	2.0
Ex-partner	1	2.0
Uncle-in-law	1	2.0
Cultural background		
Australian	20	40.8
Unknown	11	22.4
England	5	10.2
Italian	3	6.1
New Zealand/Samoan	2	4.1
Australian/Aboriginal	1	2.0
Australian/Greek	1	2.0
Australian/Maltese	1	2.0
Macedonian	1	2.0
Nepalese	1	2.0
New Zealand	1	2.0
Singaporean	1	2.0
Syrian/Iraqi	1	2.0
Religion		
Unknown	15	30.6
None	14	28.6
Catholic	11	22.4
Anglican/Church of England	3	6.1
Church of Jesus Christ	2	4.1
Buddhist	1	2.0
Orthodox	1	2.0
Presbyterian	1	2.0
Salvation Army	1	2.0

Table 2

Themes and subthemes of family experiences of consent and donation

Major themes	Subthemes
Communication	Breaking bad news
	Technical language around death and brain death
	Conversations about donation
Hospital processes and care	Clinical care
	Understanding organ donation
	Impact of donation on end of life
	Time frames to donation
Reflection on decisions and outcomes	Consolation
	Regrets
	Disappointment

process of organ donation if this took place. Participants were not asked structured questions; themes arising from interviews came from participants and were not suggested by the interviewers.

Data analysis

Interviews were transcribed verbatim by an external company and were analysed thematically by two researchers[11]. Colloquial terms such as "you know" or "I mean", and repetitive words were removed from quotes for clarity and brevity. This manuscript reports those themes associated with experiences of families. Themes were considered saturated when the interviewers concurred that no new themes were emerging from interviews. Many themes were strongly represented and much more data supporting some themes were gathered than is reported. Quotes provided are representative of the theme.

Results

Participation and demographics

Of the 123 potential donors identified, nine families were excluded as they were non–English-speaking, nine were uncontactable, and 32 consenting families were not contacted when recruitment for that group was halted. Of the 73 families contacted, 20 non-consenting families and 13 consenting families declined interview. A total of 49 participants were interviewed over 42 interviews, which took place a median of 89 (interquartile range 78 to 111) days after death of the potential donor. Demographic variables of participants are shown in Table 1.

These interviews related to 24 consent (14 DCD and 10 DBD) and 16 non-consent (13 DCD and 3 DBD) potential donor cases. Of the 24 consenting cases, there were 15 organ donors (six DCD and nine DBD), and nine potential donors who did not proceed to donation, as they were ultimately medically unsuitable, or because they died outside the timeframe for DCD. Data analysis identified three major themes and several subthemes as shown in Table 2.

Communication

Breaking bad news

Participants identified frank, plain language communication as helpful to understanding of the medical condition and prognosis of their family member.

> *Sometimes if someone tells you the truth, even if it's not what you want to hear, it's a lot easier to take that hit, deal with it and get over it and move on than it is to try and work out exactly what's going on.*
>
> *I don't like all the fluff, so I know you're trying to be nice to me but I'd rather you just tell me and I'll deal with it in my own way.*
>
> *I could see the writing on the wall but they were skirting around the issue to try and not have that discussion.*

Frequent updates on progress and changes in the family member's condition were appreciated, even if outcomes were uncertain.

> *Staff were really good…being clear, being upfront with what was happening and when they didn't know they were saying that they didn't know. That was really helpful.*

Sometimes families felt that staff tried to provide hope when the families had accepted there was no hope, and sometimes this was experienced as confusing or even frustrating.

> *I know they have to try everything but everyone was very noncommittal. They'd say, "Yeah well just keep hoping," and so what can you say, you say, "Okay sure".*

For some, receiving news that their family member would not recover was still a shock no matter how well prepared they were.

> *We were expecting it sort of all week but actually hearing it…I nearly collapsed.*

Almost all families spoke highly of the communication skills and sensitivity of the staff. Only one or two families perceived some communication as insensitive.

> *That neurosurgeon was so cruel. He said this is what happened and if it was my dad I wouldn't operate. He's got no chance, if he has one chance of survival he'll be a vegetable.*

Technical language around death and brain death

Some families expressed confusion regarding terms such as 'vegetative state', 'coma' and 'brain death' as well as 'life support'. Some families did not have a clear understanding of brain death even after their family member had donated organs.

> *The vegetative state that people are in, that's basically when they're brain dead, you can just be kept alive as a vegetable, so I guess that's what we're talking about is it?*
> *[Interviewer explains brain death]*
> *Okay, well that does clear it up because I figured that she probably just could've been kept alive, or kept functioning indefinitely.*

Some families reported that they were assisted in their understanding of brain death by seeing scans or witnessing brain death testing.

> *I said that I wanted to be there for that because, for me, I just needed to see it.*

Some indicated feeling uncomfortable about the brain death concept even after extensive conversations and decided not to be supportive of DBD, instead consenting for DCD.

> *I said I'm not letting you do anything to [son], even though he's brain dead, until the heart stops. [I wanted] to be with him, see a flat line on that machine…*

Conversations about donation

Some family members indicated that the presence of, for example, ex-partners, children or older family members who were frail, made communication regarding consent and process of donation within family meetings complex.

> *Interviewer: Would it have felt better for you to have had separate conversations with the doctors?*
> *Family: Some of it, yes, because there was a lot of tension there [with ex-wife].*

Some families reported that they were unprepared for the conversation when donation was raised, whereas others reported the opposite.

> *We were just coming to (terms with) the fact that we're losing him and they're asking us for parts of him already, that's how I felt.*

> *(When mum was) told that there was no chance of recovery…she said "okay…we'll donate his organs", (but) they hadn't got to that part of the discussion yet.*

Almost all families commented that the Organ Donor Coordinators from DonateLife who conducted the formal consent process were supportive, sensitive and knowledgeable.

> *Everyone was very professional and very calm and I felt that if we said no that was just it. There was no pressure…so I really appreciated that.*

Many families experienced some discomfort and difficulties with the discussion of the potential donor's lifestyle and medical history and with having to provide consent for each individual organ and tissue.

> *Because we're not really fully aware of [brother's] lifestyle…she felt like a bad mother…and then you go through the list; skin tissue, bone tissue, heart valves, eyes, corneas and you mentally picture a butcher's window just with parts lined up.*

Hospital processes and care

Clinical care

Family members reported high levels of satisfaction regarding the care their family member received and that staff could not have done more.

> *I definitely had a lot of faith and trust that he was going to be looked after.*

Families reported trust in the integrity of healthcare professionals caring for their family member.

> *Someone asked me after, did I think that they were almost wanting [him] to go so that he could be an organ donor? I was actually asked that by his sister and I said, "No, I never got that feeling once."*

Families spoke highly of the emotional support they received from staff.

> *Wonderful, even the receptionist, they were watching for us to come and calling us by name, coming up and giving us a hug, and the social worker, she was wonderful.*

Many family members were left with questions and expressed that, considering the process was complex and took place during a period of grief, follow-up by the hospital staff was, or would have been, appreciated.

> *To have somebody ring and say look I'm so and so and I was there and how are you doing and is there anything you want to know…that would be helpful to me just because at the time there's so much going through your mind, that you just can't process a lot of what you're being told.*

Understanding organ donation

Families reported that little or no prior knowledge or understanding of donation made having discussions and understanding processes difficult. Many families said they previously had no idea of the complexities of organ donation.

> *We didn't realise how involved it was. And I thought afterwards I've got it on my card, you can take whatever you need from me I don't care, but I didn't realise how complicated it was.*

Impact of donation on end of life

DCD involves planned withdrawal of cardiorespiratory support (WCRS), a short timeframe from declaration of death to proceeding to donation (two to five minutes), and donation may not proceed if the potential donor's circulation does not cease within a specified timeframe (currently 90 minutes in Australia) following WCRS. With respect to the WCRS prior to DCD, families' experiences differed.

> *I would've liked to have been in the room with [her] when they [turned the machines off], but they said "no you have to wait outside and then we'll call you back in". I would have liked to have been there – it may have upset me but I needed that, to be there.*

Other families indicated they wanted to leave the hospital well before WCRS for DCD.

> *So I said to [my son] I don't want to be here when he actually passes away…I've never seen anybody actually dead…and I said I don't want [your] dad to be the first one, so we left.*

Families reported good preparation for the short window of time between declaration of death and the need to proceed to the operating theatre during DCD.

> *We all knew that had to happen, we were all well aware that that was going to be the case. Well before that we had our personal time to say our goodbyes.*

Most families were well prepared that DCD may not proceed, but not all.

> *They gave us all scenarios and we were all very well informed.*
>
> *Only at the very end, once we were getting close to the one-hour mark it became evident that it was not going to proceed. Perhaps it could have been explained a little bit more.*

Many donor families chose not to see the body after the donation procedure.

> *They asked us if we wanted to see her afterwards… and they said she'd be cold and we said no we don't want to remember her like that so we just said our goodbyes.*

Time frames to donation

The logistical aspects of preparing for WCRS and the subsequent donation process can take many hours, and sometimes days. Some families experienced this extra time as tiring and stressful, while others found it useful.

> *So it prolonged the stress, it'd been a long week, a long awful week.*
>
> *So in a sense that gave us time to go home and not worry about getting a phone call in the middle of the night to say that he'd passed away.*

Families who were very supportive of donation and desired the best possible outcome were pragmatic about timeframes.

> *Well I also knew that if they waited for the heart to die a lot of (organs were) going to be wasted. I know that's a terrible thing to say but if you're going to die you may as well get something out of it.*
>
> *We basically wanted all his organs donated. So we waited for as long as possible for him to go down to have the scan, hoping (the scans would indicate brain death.)*

Reflection on decisions and outcomes

Consolation

Many families of organ donors spoke of the solace their decision, and the outcome had provided.

> *The fact that six or seven people now have a chance of life at my sister's demise made us feel incredibly good, yeah, we couldn't do anything about the first thing but we did a lot about the second thing.*

Families' experiences of communication with recipient families understandably varied.

> *I think that a good thing (has come) out of something horrible, especially when we received a thank you card the other day. You feel like someone's happy, we were sad to lose [him] but at least someone's happy.*
>
> *I chose not to open it (the letter). I will open it one day.*

Even if the donation process was difficult, families said the outcome was worth it and they would do it again.

> *What's a thorn in your leg when you've got a broken leg, it was pretty bad so a bit more bad doesn't really make it any worse.*

The research interview itself provided an opportunity to share experiences and contribute to this area of research.

> *So even the opportunity to talk to you, to potentially help your program go further forward, I think is a good thing.*
>
> *Getting it out there, it sort of helps with the bereavement side of it anyway.*

Regrets

Some reported that their decision to not donate was made under the particular circumstances at the time and, with hindsight, they would have liked to have donated their family member's organs.

> *It was just such an emotional decision and if it had been light of day you would've gone, oh god what was another six hours. I'm regretful. I am*

> *disappointed we didn't do it because I think that would be fantastic. But it didn't happen. I can't change it.*

One family who consented to kidney donation alone said:

> *We had him cremated and now I think all those organs that could've helped people have just gone up in dust.*

Disappointment

When organ donation or transplantation could not proceed, often due to the DCD timeframe, after the family had provided consent, some family members expressed disappointment.

> *I would've felt better if we could've donated the organs. I felt cheated because he didn't pass away within ninety minutes.*
>
> *I was disappointed that more couldn't have been used. More people could have benefited – that's probably the only regret.*

However, the offer of donation was sufficient for some people and they felt they had been of as much assistance as they could and that they could not influence the outcome.

> *Interviewer: Were you disappointed when donation did not proceed?*
>
> *No. The offer is the most important thing. If more people offered then rates would improve.*

Discussion

While some healthcare professionals are reluctant to request organ donation, as this may add stress for the grieving family[6], Australian data around this notion has been lacking. This study is the first to report the experiences of both donor and non-donor families in Australia and this may guide healthcare professionals' understanding of this experience and their practice. Our findings highlight that, despite the heterogeneity of backgrounds and views of potential donor families, several important themes regarding families' experience are evident.

Communication in circumstances where families are asked to consent to donation is complex, multi-layered and occurs at a time of stress and grief. Australian families highly valued direct and honest communication and were mostly very satisfied with the communication with staff, as also previously highlighted in our paper regarding consent decisions in Australian families[8]. There were very few reports of insensitive comments. This is contrary to some international reports where families perceived communication as insensitive or harsh[12]. Previous Australian data from a single hospital indicated a high level of frustration with lack of information received in the emergency department[9], whereas this was rarely perceived by participants in our study. Occasionally, some families felt healthcare staff seemed to be avoiding difficult conversations or raised hope unrealistically, which confused or frustrated them and they expressed the wish that staff had been more straightforward. These experiences should be reflected upon by healthcare staff discussing death and donation.

The formal consent process, which involves exploring the potential donor's medical history and a list of all organs and tissues to be donated, was experienced as difficult by most participants, although many said they understood the requirement, contrary to previous reports[9]. Similarly, families in our study found the Organ Donor Coordinators sensitive and supportive of their decisions, while previous Australian studies indicated that families often felt unsupported and highlighted the need for counselling during and after the donation process[9,13]. Support is now offered to all donor families (but not declining families) by DonateLife via Family Support Coordinators. Many families in our study were using these or other counselling services and there was little mention of feeling unsupported.

Despite the short timeframe between the death and the interview—around three months—many family members commented that conversations with clinical staff seemed like a blur, and many still did not fully understand aspects of the process, or the concept of brain death. Extensively described in the international literature[14,15] is the confusion about when brain dead patients actually die and the role of cardiorespiratory support; this was illustrated in our study by one donor family member stating he thought his partner "*could've been kept alive, or kept functioning indefinitely".* While there is no consensus on the impact of brain death understanding on consent to donation[8,15–17], it is likely that lack of understanding influences a family's experience of the process. Some families expressed feelings of confusion; being present at brain death testing or seeing visual information assisted some families with understanding. Our results showed that in some cases DCD may be an acceptable alternative for families unwilling to consent to DBD.

A desire for follow-up by clinical staff involved in the care to enable better understanding of events was expressed. Although routine follow-up requires time from already busy clinical staff, it may provide improved clarity for families. Many used the interview as an opportunity to ask questions and clarify misunderstandings and saw participation in the study as a positive event, consistent with previous studies[18,19].

Almost all potential donor families expressed a high level of trust in, and respect for their healthcare professionals and most felt that they, and their family member, had received very high levels of personal and clinical care. This differs from some international literature, where potential donor families often expressed a lack of trust in the healthcare professionals[20], and concerns about whether enough had been done to save the potential donor and the transparency of donation processes[21].

Our findings demonstrate some important principles for those preparing families for DCD. It was very important for families to be fully prepared for the short timeframe between declaration of death and proceeding to donation, the possibility that donation would not proceed if the circulation did not cease within the required timeframe, and that the number of organs suitable for donation decreased with time following WCRS. When DCD was able to proceed, families said they were well prepared for only having a few minutes to say goodbye. Most, but not all, families understood the timeframe within which death must occur for donation to proceed and when donation did not occur there was often a sense of disappointment, particularly if families were not well prepared for this outcome.

The time period between consent and donation was perceived by many family members as long and stressful, as has been previously noted[9], although some families said it gave them extra time to say goodbye and to gather family. This divergence in donor families' perception of this time after the decision has previously been described[22] and highlights the importance of an individual approach. Pragmatism also influenced families' experiences of these timeframes, as those who had decided to donate supported procedures that maximised donation outcomes.

Importantly, although many said the process was lengthy and stressful, these difficulties and other barriers were often not significant enough to adversely affect their satisfaction with the outcome of the process. While performance in donation and transplantation sectors is mostly assessed on consent, donation and transplantation rates, the experiences of families who have been through the processes of consent and donation are also important outcomes. Clearly, those who felt that the communication, preparation and care that they experienced were of a high standard would perceive greater satisfaction, and potentially be more likely to have favourable attitudes toward donation in the future.

Although many aspects of the organ donation process required extra time or effort from families at an already sad and stressful time, they overwhelmingly agreed that, on reflection, the knowledge that their family member had saved or improved the lives of others was worth the stress they experienced. Donor families had no regrets about donation and indicated that, in general, donation provided some consolation during their grief, similar to previous data[10,13,22,23]. However, regret was expressed by some family members declining donation, consistent with reports indicating regret is more common among non-donor families[24,25], and some consenting families whose family member was unable to donate organs were disappointed with the outcome. Some of these families received solace from eye and tissue donation and health professionals seeking consent should emphasise the benefits of tissue donation if appropriate.

Limitations

This study included families with a wide variety of backgrounds, however non–English-speaking families could not be included due to a lack of funds to hire interpreters. Because their experiences could not be included, our results cannot be generalised to the wider Australian population. More research assessing experiences of non–English-speakingfamilies is urgently needed to explore their experiences, further improve services and provide everyone with the opportunity to donate. We were unable to assess the influence of whether the hospital staff involved were trained and/or specialised in organ donation as there was usually a large number of staff members involved in the conversations and their individual contribution could not be assessed.

Conclusion

Our findings further aid the understanding of factors affecting Australian families' experiences and degree of satisfaction with donation requests and processes. These findings may further assist healthcare professionals' practice and may ultimately affect donation processes and outcomes[26].

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