Towards a national model for organ donation requests in Australia: evaluation of a pilot model

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ABSTRACT

Objective: To evaluate whether structural elements of a collaborative requesting model were observed in practice, and explore the impact of specialised communications training and elements of the model on consent rates.

Design: A national observational study captured staff observations of the organ donation requesting process.

Setting: DonateLife staff in 15 hospitals collected data from medical, nursing and allied health professionals who participated in the donation requesting process over a 12-month period.

Participants: Data were collected from 201 family donation conversations (FDCs).

Main outcome measures: Whether structural elements of the model were observed in practice, and rates of consent to donate.

Results: For most cases, there was a team planning meeting (87.0%); a gap in time between the meeting at which family understands brain death or the inevitability of death and the FDC for most cases (72.0%); and at least one trained requester present at the FDC (80.7%). Consent rates were significantly different according to who led the FDC: an untrained treating clinical specialist (45.2%); a trained treating clinical specialist (54.8%); or a trained requester who was not part of the treating clinical team (74.5%) ($\chi^2 = 11.92$, $P = 0.003$). Logistic regression showed that the odds ratio (OR) for consent was significantly greater when the patient was on the Australian Organ Donor Register (OR, 9.3; CI, 3.5–24.5) and when the FDC was led by an FDC-trained requester who was not part of the treating clinical team (OR, 6.8; CI, 2.3–19.9).

Conclusions: Structural elements of the model were observed in most cases, indicating that the model is feasible and acceptable. We showed that the highest consent rates were achieved when FDCs were led by professionals who had completed the specialised communications training and were not part of the treating clinical team for that patient.

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Historically in Australia, organ donation has been raised by a senior intensive care clinician during end-of-life care discussions. According to previous research, the level of training and experience of health professionals who raise the option of organ donation with families is the factor most consistently identified as influencing the decisions of families about donation.[1-3] A national professional education package is a key strategy in the Australian Government's 2008 National Reform Programme for improving organ and tissue donation rates.[4,5] The package promotes an approach to requesting organ donation that is described as the collaborative model.

The model aims to ensure that a trained health professional is present at the time that organ donation is first raised with the family, after the family understands that death has occurred or is inevitable. Having an appropriately trained health professional present as part of routine practice is intended to provide families with timely and sufficient information about the opportunity of organ and tissue donation so they can make a fully informed and enduring decision that is right for them.

The model is based on emerging evidence that the involvement of a specialist "requester", who is not part of the treating clinical team, may provide a better experience for families and increase consent rates.[6-8] The model encourages the early involvement of a donation specialist requester who is trained in the family donation conversation (FDC), and who is not part of the treating clinical team for that patient. A donation specialist requester is usually a health professional with dedicated responsibility for organ and tissue donation within that hospital and may be medical (usually with an intensive care background) or nursing staff. Involvement of the donation specialist requester encourages conduct of a team meeting to plan the most appropriate approach to requesting donation, including roles and responsibilities for professionals involved in the FDC.

Specialised communications training is delivered through staged units, the first being the core FDC module, which provides theory and understanding of family grief and communication, informed decision making and skills practice. The second unit is the practical FDC module, which provides an opportunity for focused skills practice and exploration of responses to family concerns. The content of the core and practical FDC modules is based on training and education programs developed and delivered in collaboration with the Gift of Life Institute in the United States.[9]

Table 1. Characteristics of potential donors

Characteristic	Value
Sex (*N* = 184)	
Male	118 (64.1%)
Female	66 (35.9%)
Age, years (*N* = 181)	
0–4, *n* (%)	5 (2.8%)
5–17, *n* (%)	8 (4.4%)
18–24, *n* (%)	7 (3.9%)
25–34, *n* (%)	18 (9.9%)
35–44, *n* (%)	24 (13.3%)
45–54, *n* (%)	46 (25.4%)
55–64, *n* (%)	29 (16.0%)
65–74, *n* (%)	28 (15.5%)
75–84, *n* (%)	15 (8.3%)
⩾ 85, *n* (%)	1 (0.6%)
Mean, years (SD)	49.5 (19.4)
Range, years	0–87
Main cultural background, *n* (%) (*N* = 176)	
Australian, New Zealand	138 (78.4%)
European	12 (6.9%)
North African and Middle Eastern (incl. Jewish, Iraqi and Lebanese)	4 (2.3%)
Asian (incl. North East and South East)	15 (8.5%)
Southern and Central Asian (incl. Afghan, Indian and Pakistani)	3 (1.7%)
American (incl. North, South and Central American)	0 (1.1%)
Sub-Saharan African (incl. South African and Kenyan)	2 (1.1%)
Pacific Islands	2 (1.1%)

Structure of the request process

The core structural elements of the model for requesting organ and tissue donation are:

1. A conversation about brain death or the inevitability of death (meeting about death): there is a sensitive separation (gap in time or clear separation) after this meeting and before discussion about donation.
2. A team planning meeting (before or after the meeting about death): the treating clinical team, an FDC-trained requester who is not on the team, and any other relevant staff, meet to plan the FDC (and, if relevant, the meeting about death).
3. The FDC meeting: families are given information and an opportunity to ask questions before making a decision about donation. At least one FDC-trained requester who is not the treating clinical specialist should be present at this meeting, ideally leading or coleading the conversation.

Table 2. Characteristics of next of kin

Characteristics of family or next of kin	Value
Language spoken most comfortably, *n* (%) (*N* = 178)	
English	154 (86.5%)
Bilingual (English and other)	9 (5.1%)
Language other than English	15 (8.4%)
Religious affiliation, *n* (%) (*N* = 145)	
Christianity (Orthodox, Catholicism, Other)	69 (47.7%)
No religious affiliation	60 (41.4%)
Islam	3 (2.1%)
Hinduism	2 (1.4%)
Buddhism	9 (6.2%)
Other	2 (1.4%)

The model recognises that the circumstances surrounding each death will affect the way organ and tissue donation requesting occurs, but regards these structural elements to be appropriate and desirable in all instances. The model encourages a team-based approach with flexibility in how roles are implemented among appropriately trained and qualified health professionals. Information is provided to families so they can make an informed and enduring decision that is best for them and their family member, regardless of whether their decision is to agree to or decline donation.

Our aims were to establish whether the structure of the model for requesting was observed in practice and to assess whether specialised communication training is associated with increased organ donation consent rates.

Methods

Design

The evaluation captured information about all conversations requesting organ donation that took place in a 12-month period at 15 participating sites across Australia during the pilot period from March 2013 to March 2015. Details of the processes and survey data from staff present when organ donation was first raised were used to assess whether elements of the model were observed in practice and to predict outcome (consent or decline).

Two purpose-designed instruments were used:

- Process survey: a summary record of the process followed during each donation request, including which meetings were held, how long they lasted, where the meetings took place, the number of people present at each (staff and families) and whether staff had received FDC training. The treating clinical specialist who had identified a patient as a potential donor was responsible for completing this survey, although the individual who completed the factual record could be another staff member under the direction of the treating clinical specialist.

Table 3. Elements of collaborative requesting model, first two meetings

Meeting 1* (meeting about death) ($N = 177$)	Value†
Duration, minutes	
< 10 (%)	11 (6.2%)
11–20 (%)	66 (37.3%)
21–30 (%)	59 (33.3%)
31–40 (%)	16 (9.0%)
41–50 (%)	14 (8.0%)
51–60 (%)	8 (4.5%)
> 60 (%)	3 (1.7%)
Mean (SD)	29.1 (18.9)
Minimum	10
Maximum	180
Family raised concept of donation, *n* (%)	40/136 (29.4%)
When donation raised, sensitively deferred, *n* (%)	26/37 (70.3%)
Meeting 2 (team planning meeting) ($N = 158$‡)	
Duration, minutes	
< 5 minutes	52 (32.9%)
6–10 minutes	63 (39.9%)
11–15 minutes	21 (13.3%)
16–20 minutes	14 (8.9%)
21–25 minutes	0 (0.0%)
26–30 minutes	7 (4.4%)
> 30 minutes	1 (0.6%)
Mean (SD)	11.0 (7.4)
Minimum	1
Maximum	60
Meeting 2 occurred before Meeting 1 ($N = 161$)	77 (47.8%)
Meeting 2 occurred after Meeting 1 ($N = 161$)	84 (52.2%)

* Meeting at which family accepts death or its imminence.
† Percentages based on valid responses only. ‡ Except where indicated otherwise.

Table 4. Elements of collaborative requesting model, third meeting

Meeting 3 (family donation conversation)	Value*
Duration, minutes ($N = 175$)	
< 10	25 (14.3%)
11–15	24 (13.7%)
16–20	26 (14.9%)
21–25	9 (5.1%)
26–30	47 (26.9%)
31–35	2 (1.1%)
36–40	15 (8.6%)
41–45	4 (2.3%)
46–50	4 (2.3%)
51–55	0 (0.0%)
56–60	12 (6.9%)
> 60	7 (4.0%)
Mean (SD)	29.3 (19.0)
Minimum	2
Maximum	120
FDC-trained staff present, *n* (%) ($N = 176$)	
0	34 (19.3%)
1	75 (42.6%)
2	50 (28.4%)
⩾ 3	17 (9.7%)

FDC = family donation conversation. * Percentages based on valid responses only.

- FDC survey: a brief survey for any health or allied health professionals involved in each FDC. The survey recorded observations and opinions about the process followed in each conversation, including topics discussed at each meeting and opinions about the conduct of the meetings. DonateLife Network members involved in data collection encouraged all staff present in any FDC to provide data.

We obtained ethics approval from the Australian Department of Health and Ageing, relevant state and territory health departments and health institutional human research ethics committees for each hospital.

Data analysis

We show descriptive statistics as means with SDs. Categorical data are shown as raw numbers and percentages. In cases where data were missing, no assumptions were made and percentages represent proportions of valid responses only. Data analysis was performed using SPSS, version 22.0 (SPSS Statistics). For categorical variables, we used χ^2 tests, and we used logistic regression analysis to explore the relative contribution of key variables of the model in predicting higher consent rates. For all inferential analyses, alpha was set at 0.05 and two-tailed tests of significance were used.

Results

Cases studied

There were 201 organ and tissue donation conversations for which at least one process survey and/or at least one FDC survey were received. Specifically, 186 completed process surveys and 348 completed FDC surveys were received, which represented 155 linked FDC cases.

Demographic information

Basic demographic information was recorded about the potential donor (Table 1) and the next of kin (Table 2). For cases in which the donation pathway was reported (173 cases), just over half were donation after brain death (56.1%

Table 5. Association between patient and collaborative requesting model characteristics (bivariate χ^2 analyses)

Characteristic	Donation consent		Bivariate test	
	Consented, *N* (%)	Declined, *N* (%)	χ^2	*P*
Patient's wishes recorded on AODR				
Yes	54 (87.1%)	8 (12.9%)	24.89 (1, *N* = 158)	< 0.001
No	46 (47.9%)	50 (52.1%)		
Team planning meeting held				
Yes	100 (63.3%)	58 (36.7%)	–	NS
No	15 (65.2%)	8 (34.8%)		
Gap in time between meeting about death and FDC				
Yes	79 (60.3%)	52 (39.7%)	–	NS
No	37 (72.5%)	14 (27.5%)		
FDC-TR present at FDC				
Yes	97 (69.3%)	43 (30.7%)	8.08 (1, *N* = 182)	0.004
No	19 (45.2%)	23 (54.8%)		
FDC led by TCS				
Yes	44 (51.8%)	41 (48.2%)	10.24 (1, *N* = 167)	0.001
No	62 (75.6%)	20 (24.4%)		
FDC led by FDC-TR				
Yes	87 (69.6%)	38 (30.4%)	11.08 (1, *N* = 167)	0.004
No	19 (46.2%)	23 (54.8%)		
FDC leader				
TCS not FDC-trained	19 (45.2%)	23 (54.8%)	11.92 (2, *N* = 167)	0.003
TCS FDC-trained	17 (54.8%)	14 (45.2%)		
FDC-TR, not part of treating clinical team	70 (74.5%)	24 (25.5%)		

AODR = Australian Organ Donor Register. NS = not significant. FDC = family donation conversation. FDC-TR = FDC-trained requester. TCS = treating clinical specialist.

[97 cases]) and 42.2% (73 cases) were donation after circulatory death (three cases were described as "both").

The patient was registered on the Australian Organ Donor Register (AODR) in 38.5% (62/161) of cases. Comparison with the DonateLife audit figures over the same period suggested that very few FDCs were not captured and that there was no systematic bias in the FDCs captured during our pilot.

Request process

The FDC survey captured information about the way in which the donation-requesting process was conducted (Table 3 and Table 4). Characteristics of the model were observed in most cases.

A team planning meeting was held in 87.0% of cases (161/185), with most lasting for 15 minutes or less (86.1%). At least one FDC-trained requester was present in nearly all team planning meetings (144/157 cases [91.7%]), and two were present in most cases. In most cases (115/143 cases with relevant data [80.4%]) there was an FDC-trained requester present who was not the treating clinical specialist.

The team planning meeting was held before or after the meeting at which the family understood that death had occurred or was inevitable. For 134/186 cases (72.0%), there was a gap in time between the meeting about death and the FDC. Regardless of whether there was a reported time gap between the meeting about death and the FDC, for nearly all cases (147/160 cases [91.9%]), staff who reported on what they observed agreed that "there was a clear separation between the conversation in which the family understood death and the FDC". In 33/38 cases (86.8%) when there was no time gap, respondents said that there had been a "clear separation" between the two conversations.

Organ donation decision

At the end of the requesting process, consent to donate was provided for 63.5% of cases (120/189).

Consent rates were associated with several variables related to the model, including whether or not the patient was registered on the AODR, the presence of an FDC-trained requester during the FDC, and who led the FDC. There was no association between consent and whether or not a team planning meeting was held, or whether there was a gap in time between the meeting about death and the FDC (Table 5).

Table 6. Association between patient and collaborative requesting model characteristics (multivariate logistic regression tests)*

	Multivariate tests							
Characteristic	OR (CI)	*P*	OR (CI)	*P*	OR (CI)	*P*	OR (CI)	*P*
Patient's wishes recorded on AODR	7.70 (3.22–18.46)	< 0.001	7.65 (3.07–19.04)	< 0.001	8.25 (3.30–20.67)	< 0.001	9.27 (3.51–24.47)	< 0.001
Team planning meeting held								NS
Gap in time between meeting about death and FDC							0.31 (0.12–0.82)	0.018
FDC-TR present at FDC	3.51 (1.49–8.30)	0.004						
FDC led by someone other than TCS			3.06 (1.43–6.55)	0.004				
FDC led by FDC-TR					3.17 (1.34–7.48)	0.008		
FDC leader								
TCS not FDC-trained								0.002 (main effect)
TCS FDC-trained								NS
FDC-TR, not part of treating clinical team							6.75 (2.29–19.86)	0.001

OR = odds ratio. AODR = Australian Organ Donor Register. NS = not significant. Shaded areas = variable not included. FDC = family donation conversation. FDC-TR = FDC-trained requester. TCS = treating clinical specialist. * Empty cells indicate data not included.

When an FDC was led by a treating clinical specialist, consent was not associated with whether or not the treating clinical specialist was trained (Table 5). The consent rate was higher when the FDC was led by someone not on the treating clinical team, rather than the treating clinical specialist (trained or untrained) (Table 5). The consent rate for an FDC led by a trained requester who was not on the treating clinical team was significantly higher (74.5%) than when the FDC was led by an FDC-trained treating clinical specialist (54.8%) ($\chi^2(1, N = 125) = 4.25$; $P < 0.05$).

Predicting consent

We conducted logistic regression analyses to predict consent for the outcome of the FDC. Because of the strong association between consent and the patient being on the AODR, we entered variables reflecting who was present and who led the FDC into separate logistic regression analyses with AODR included as a variable. Having an FDC-trained requester present was a significant predictor of consent (odds ratio [OR], 3.51; CI, 1.49–8.30, as was the training status of the person who led the FDC (OR, 3.17; CI, 1.34–7.48). An FDC led by someone not on the treating clinical team also had a higher likelihood of consent than one led by the treating clinical specialist (OR, 3.06; CI, 1.43–6.55) (Table 6).

We categorised cases into three groups, according to whether the person who led the FDC was the treating clinical specialist but not FDC trained, the treating clinical specialist and FDC trained, or FDC trained but not part of the treating clinical team. We conducted a final regression with the 147 cases, with data on all five predictor variables: whether the patient was on the AODR; whether a team planning meeting was held; whether there was a gap in time between the meeting about death and the FDC; whether the person who led the FDC was FDC trained; and whether the person who led the FDC was on the treating clinical team.

Overall, the predictors reliably distinguished between those who consented to donate and those who declined ($\chi^2 = 44.23$, $P < 0.001$, df = 5) (Table 6). We found that Nagelkerke $R^2 = 0.354$, which indicated a moderate relationship between prediction and grouping. Prediction success overall was 71.4 (87.0% for consent and 45.5% for decline).

Being on the AODR register was associated with higher donation rates (OR, 9.27; CI, 3.51–24.47), as was the role and training status of the person who led the FDC, ie, there was a significantly higher likelihood of consent when the FDC was led by a trained requester who was not part of the treating clinical team (OR, 6.75; CI, 2.29–19.86). Having a team planning meeting was not a significant predictor of consent ($P = 0.47$), although the number of cases where there was no team planning meeting was small, so the power to find an effect was low. When there was a gap in time between the meeting confirming the family's understanding of death and the FDC, the odds of consent were much lower (OR, 0.31; CI, 0.12–0.82), even though this was only a trend in the univariate analysis.

Discussion

Our evaluation showed that the structural elements of the model, in particular the conduct of a team planning meeting and a separation between the meeting about death and the FDC, were observed in practice in most cases. Qualitative information available through the evaluation suggested that the exact process followed for each FDC was influenced by several variables, including patient, family and contextual factors. The finding that a gap in time between the meeting about death and the FDC predicted a lower likelihood of consent may reflect the complexity of implementation of the structural elements. It is plausible that the cases with no separation included the least complex cases, in which families quickly accepted death and agreed to consent to donation. Our result reflects findings from some other studies, but we did not reach the same conclusion that it is not good practice to separate the conversations about brain death and donation requesting and that donation should be requested before or during notification of brain death.[6] Requesting organ donation is a complicated behaviour conducted in a complex setting, and we recognise that flexibility is a necessary component of a best-practice model. We propose the role of the FDC-trained requester as a mechanism to ensure that variation in implementation of the model is appropriate for the needs of each family and each case.

We found evidence that specialised communication training had a positive impact on organ donation consent rates. Consent rates were higher when the FDC was led by an FDC-trained requester, regardless of the structural elements of the consent process. We also found evidence of a significantly higher likelihood of consent to donate when the FDC was led by an FDC-trained requester who was not a member of the treating clinical team, compared with a treating clinical specialist not trained in the FDC. The consent rate for FDCs led by a treating clinical specialist with specialist communication training fell between the two other groups, and was significantly lower than when the process was led by the FDC-trained requester who is not part of the treating clinical team for that patient.

Ours was a relatively small study, involving 15 hospitals willing to commit to implementing the model. FDC-trained staff represented early adopters of FDC training, who may have had particular personal characteristics and experience that contributed to the success of the requesting model. Another possible limitation of our study was that we were not able to use a randomised design, so observed associations may have been due to factors other than the collaborative requesting model or FDC training. However, given the challenges of performing studies in this area of complex behaviour, and the potential that strict adherence to step-by-step protocols would be inappropriate to organ donation requesting practice, our study contributes to existing evidence and ongoing discussion.

Conclusion

Our results reflect other emerging evidence and provide strong support for the importance of specialised communication training in conducting FDCs. They also support the potential value of having the FDC led by a trained specialist requester who is not part of the patient's treating clinical team.

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Competing interests

None declared.

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