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Results of an evaluation of a pilot of models for requesting organ and tissue donation in Australia

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- Royal Darwin Hospital
- Austin Hospital
- Footscray Hospital
- Townsville Hospital
- Tweed Hospital
- Royal Prince Alfred Hospital
- Princess Margaret Hospital
- John Hunter Hospital
- St George Hospital
- Northern Hospital
- Royal North Shore Hospital
- Prince of Wales Hospital
- Liverpool Hospital

Results of an evaluation of a pilot of models for requesting organ and tissue donation in Australia

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Project commissioned by the Organ and Tissue Authority (OTA)

BACKGROUND

A pilot of models for requesting organ and tissue donation was conducted in hospitals around Australia from March 2013 to May 2015. The training, education and experience of health professionals who raise the opportunity of donation with families is the factor most consistently identified in the literature as influencing families' decisions to donate. Based on this evidence, the "Collaborative Requesting Model" (CRM) is focused on ensuring that a trained health professional is present at the time that organ and tissue donation (OTD)¹ is first offered to the family in a hospital setting. A national Professional Education Package (PEP) provides education and training to support professionals to engage families in conversations about the opportunity for organ and tissue donation². Specialist training to support the CRM is delivered through three staged and sequential units of training, including an introductory unit based on the Australasian Donor Awareness Program (ADAPT), followed by the Family Donation Conversation (FDC) Core Module and FDC Practical Module. The Core Module provides theory and understanding of family grief and communication, and informed decision making; the Practical Module provides an opportunity for skills practice and exploration of responses to family concerns. Completion of the Core FDC Workshop and the Practical FDC Workshop was a prerequisite requirement for the 'FDC trained requesters' involved in the models being evaluated in the 15 pilot hospitals. An education package to support the pilot and the introduction of the CRM was provided in each hospital before commencement of the pilot.

The main features of the CRM are that the opportunity for donation will only be raised with a potential donor family after the family understands the death or the inevitability of death of their family member. Donation will not be raised by the Treating Clinical Specialist in conversations with the family about death or prognosis. Techniques to sensitively separate these conversations, particularly where the family raises donation early in the process, are part of the training being provided to clinical specialists. The separation of conversations enables the treating clinical team and the donation specialist requester to collaboratively meet and plan their respective roles and approach before the donation conversation with the family. The CRM is intended to encourage a team-based approach with flexibility in how roles are implemented across appropriately trained and qualified health professionals. The trained requester may be the Treating Clinical Specialist or a health professional who is not part of the treating clinical team but has completed specialised communication training in how to conduct Family Donation Conversations (FDC). Ideally, under the CRM, the conversation in which donation is raised with a family for the first time is conducted collaboratively with the Treating Clinical Specialist and an FDC Trained Requester.

The Australian Institute for Primary Care & Ageing (AIPCA) at La Trobe University was commissioned by the Organ and Tissue Authority (OTA) to undertake an evaluation of the pilot. The evaluation captured detailed

¹ The project scope was the requesting processes associated with donation after brain death and circulatory death including organ and tissue donation. It did not include requesting processes for tissue-only donation outside of the hospital.

² National Reform Program objectives and elements. Available at: <http://www.donatelife.gov.au/about-us/national-reform-programme> Last accessed June 2015.

information about the process in each case a potential donor was identified in participating hospitals during a 12 month period. The evaluation design recognises the complexity of the context in which requesting organ and tissue donation takes place, and the complex nature of the requesting behaviour. Each FDC case is a unique and dynamic combination of the characteristics of the patient (including the potential pre-existing indication of their consent through the Australian Organ Donor Register (AODR)) and their family (or next-of-kin), the physical time and setting in which the event is taking place, and the characteristics, skills and opinions of health practitioners. Information about the context, processes and behaviours, as well as the observations and opinions of participants enables an in-depth understanding of each FDC. Recent writing about implementing complex interventions in complex systems suggests that the way to maintain fidelity of an intervention in these kinds of situations is to think about the purpose or function of different components, rather than trying to impose the same form of components in different settings. "This allows adaptation to context while maintaining fidelity."³ The CRM recognises that the exact process followed for each FDC will be influenced by a range of factors; however, the role of the FDC Trained Requester is central to ensuring that variation in implementation of the CRM is appropriate for the needs of each family and that the experience of families involved in OTD will be positive.

The evaluation sought to answer six key questions:

1. Was the structure of the Collaborative Requesting Model (CRM) observed in practice?
2. Were the elements of the specialised communication training observed in practice?
3. Did Trained Requesters feel that the specialised communication training has equipped them with the required skills to discuss donation with the family?
4. Was the model effective in providing sufficient information to families/next-of-kin to support decision making?
5. What was the impact of specialised communication training and elements of the different requesting model on organ donation consent rates?
6. Did the knowledge, attitudes and beliefs of Hospital Intensive Care and Emergency Department staff support donation?

DonateLife staff in participating hospitals collected data from medical, nursing and allied health professionals who took part in the FDC requesting process. Two surveys (known as Tools 2 and 3) were designed and used to capture the process in detail, and to record the opinions and perceptions of staff about each meeting that took place, as well as the outcome of each FDC in terms of consent or refusal to donate.

- **Tool 2: Record of Donation Requesting Process:** This tool provided a summary record of the process followed during each donation request including noting the number of people present and where the meetings and conversations took place. Responsibility for completing this tool rested with the Treating Clinical Specialist who identified a patient as a potential donor, although the individual who completed the factual record could be another staff member under the direction of the Treating Clinical Specialist. If for any reason the data about the FDC could not be collected contemporaneously as intended, the DonateLife staff member used records and follow-up with staff in person for any missing information.
- **Tool 3: Feedback about Family Donation Conversation:** This tool provided a survey of the views of health professionals participating in each Family Donation Conversation. This tool was offered to any health and allied health professionals involved in each Family Donation Conversation to

³ Hawe, P. (2015) Lessons from Complex Interventions to Improve Health. *Annual Review of Public Health*.36:307-323. Downloaded August 2015

complete, and asked for their observations and opinions about the process that was followed in each conversation. Issues of validity and reliability were addressed by asking DonateLife team members involved in data collection to encourage all those present in any FDC to provide data about what occurred in the meeting.

The data from Tools 2 and 3 were analysed by AIPCA to establish the extent to which the different characteristics of the proposed CRM were present, to evaluate the impact of the FDC training on the way health professionals manage conversations with families when discussing OTD, and consent rates. The evaluation also collected data through a survey (known as Tool 1) from staff in the participating hospitals' Emergency Departments (EDs) and Intensive Care Units (ICUs) prior to and after the monitoring of FDCs to consider the organisational environment in which OTD practice is being implemented.

ABOUT THE CONVERSATIONS OBSERVED

There were 186 completed Tool 2 surveys returned and 348 Tool 3 surveys. Together they referred to 201 cases in which family donation conversations were undertaken. There was a Tool 2 and at least one Tool 3 survey that could be linked to the same conversation for 155 cases.⁴ The number of surveys returned from each hospital varied according to the number of potential donors identified at the hospital during the period of the pilot study. The number of cases for which there was data varied from 3 to 30 across participating hospitals.

Key features of Family Donation Conversation (FDC) cases

A range of information was available about the potential donors and their families or next of kin.

- More of the potential donors were male (118 cases) than female (66 cases).
- Ages ranged from 0-87 years. (There was 1 newborn and four children under the age of 4 yrs.)
- Just over three-quarters were described as being of Australian or New Zealand cultural background (78.4% - 138 of 176 cases).
- English was the language spoken "most comfortably" in most cases (86.5% - 154 of 178 cases).
- There were five or more family members present and involved in the meetings in almost half of the cases (45.1% 83 of 184 cases). In about one-fifth of cases there were 2 (17.9% - 33 cases), 3 (17.9% - 33 cases) or 4 (14.7% - 27 cases) family members involved.

Where reported (173 cases), just over half of the cases were donation after brain death (DBD) (56.1% - 97 cases) while 42.2% – 73 cases were cases of donation after circulatory death (DCD) (there were three cases described as "both DBD and DCD").

A family decision on donation was reached by the end of the initial FDC in 83.8% of cases (150 of 179 cases). In the remaining cases, the decision on donation was made after this initial meeting. Based on information available from written comments, it appeared that a decision was made subsequently, either following multiple discussions exploring OTD or because the family took time to consider their views and then returned to give a decision.

At the end of the process, consent to donate was provided in 63.5% of cases (120 of 189 cases). The consent rate was very similar for cases of DBD than DCD (65.6% - 63 of 96 cases compared with 64.4% - 47 of 73 cases).

⁴ Unless otherwise stated, percentages are based on valid responses only.

OTD REQUESTING PRACTICE OBSERVED: STRUCTURE

1. Was the structure of the Collaborative Requesting Model (CRM) observed in practice?

Meeting 1: Understanding Death

The first meeting under the CRM is one in which the family comes to understand that their loved one has died or that treatment is to be withdrawn in the expectation of death.

The duration of most meetings was half an hour or less (76.8%, mean = 29.1 minutes, SD = 18.9 minutes). The meetings were generally held in a “family” or “meeting room” (30.8% - 56 of 182 cases) or another private room (56.0% - 102 of 182 cases). In 60.1% of cases (101 of 168 cases) there were 3 or more staff present.

The family raised the issue of donation in the meeting about death in almost one-third of cases (29.4% - 40 of 136 cases). In the majority of cases (70.3% - 26 of 37 cases) respondents thought that discussion about OTD was “sensitively deferred”. A response was not provided for 3 cases.

Meeting 2: Team Planning Meeting

The second meeting in the CRM model is the Team Planning Meeting. This meeting involves the treating clinical team and the FDC Trained Requester to plan the FDC and agree on team roles for the conversation in which organ donation is initially requested.

Team Planning Meetings were conducted in 87.0% of cases (161 of 185 cases). Most planning meetings took 15 minutes or less (86.1% - 136 of 158 cases; mean = 11.0 minutes, SD = 7.4 minutes). The planning meeting was held before the meeting at which the family understands death in 47.8% of cases (77 of 161 cases).

At least one FDC Trained Requester was present in nearly all cases (91.1% - 144 of 158 cases). There were two FDC trained staff present in a large proportion of cases (41.4% - 65 of 157 cases), followed by one (38.2% - 60 of 157 cases). In 12.1% of cases there were three or more FDC-trained staff present (19 of 157 cases). In the majority of cases (80.4% - 115 of 143 cases), there was an FDC Trained Requester present who was not the Treating Clinical Specialist.

When respondents were asked if they had any other comments about this meeting, several respondents took the opportunity to note that a Team Planning Meeting was not held or that not all relevant staff were present (“Prefer to have entire team present for pre-meeting”). Others noted that there were several planning meetings held (“Series of conversations rather than single planning meeting occurred”).

Meeting 3: Family Donation Conversation (FDC)

The third meeting in the CRM is the Family Donation Conversation (FDC). During this meeting the first request for organ donation is made. Families are given information to assist them to make a decision with which they are likely to feel comfortable with in the future.

The duration of the FDC was 30 minutes or less in 74.9% of cases (131 of 175 cases; mean = 29.3 minutes, SD = 19.0 minutes). In most cases, the respondents considered that the meeting was “about the right length”. In 72.0% of cases, respondents recording the process through Tool 2 indicated there was a time gap between Meeting 1 and Meeting 3 (134 of 186 cases). Regardless of whether there was a reported time gap between Meeting 1 and Meeting 3, informants reporting on what they observed (Tool 3) agreed that “there was a clear separation between the conversation in which the family understood death...and the

FDC” in nearly all cases (91.9% or 147 of 160 cases). Of the 38 cases where data indicated there was no time gap, in 33 cases (86.8%), respondents said that there had been a clear separation between the two conversations.

At least one FDC Trained Requester was recorded as present in the majority of cases (80.7%, 142 of 176 cases). In most cases there was one FDC Trained Requester (42.6% - 75 cases) or two FDC Trained Requesters (28.4% - 50 cases) present, with three or more FDC-trained requesters present in the remaining cases (9.7%, 17 cases). There was no FDC Trained Requester recorded as present in around one-fifth of cases where information was available (19.3% - 34 of 176 cases). These figures may be a conservative estimate, as the training status of all staff members present was not always known by staff observing the process.

The leadership of the FDC was explored further and categorised according to roles and FDC training:

- In 55.6% of cases the FDC **was led by a Trained Requester who was not the Treating Clinical Specialist** (or was co-led with a Treating Clinical Specialist). In some cases, there was only one FDC Trained Requester present.
 - In 35.7% of cases the FDC was led by an FDC Trained Requester and a trained or untrained Treating Clinical Specialist was present
 - In 7.0% of cases the FDC was reportedly “co-led” (specifically noted in the survey⁵) by an FDC Trained Requester and a Treating Clinical Specialist (trained or untrained)
 - In 12.9% of cases the FDC was led by the FDC Trained Requester with no Treating Clinical Specialist present
- In 19.3% of cases the FDC **was led by a Treating Clinical Specialist who was trained** with or without another FDC Trained Requester present
 - In 11.1% of cases the FDC was led by the Treating Clinical Specialist who was the only FDC Trained Requester present
 - In 8.2% of cases, the FDC was led by the Treating Clinical Specialist who was FDC trained and an FDC Trained Requester was also present
- In 25.1% of cases the FDC **was led by a Treating Clinical Specialist who was not an FDC Trained Requester**, with or without another FDC TR present
 - In 20.4% of cases the FDC was led by the Treating Clinical Specialist who was not FDC trained (and there was not an FDC Trained Requester present).
 - In 4.7% of cases, the FDC was led by the Treating Clinical Specialist who was not FDC trained, but an FDC Trained Requester was present

Conclusion – OTD requesting practice observed: structure

In the majority of cases, the process followed was generally consistent with the FDC training. All three meetings took place in most cases (87.0% - 161 of 185 cases) and in more than two-thirds of cases (65.4% - 121 of 185 cases), all three meetings took place AND there was a gap between the meeting informing families about death and the conversation requesting donation. In 142 cases (80.7% of the total) an FDC-trained requester was present in the FDC meeting. The data indicated that, in general, the meetings were held in a manner that was consistent with FDC training. That is:

- the majority of cases reflected the key structural elements of the CRM
- there was evidence of conscious flexibility in implementation of the CRM, generally with the intent to better support families’ needs in specific circumstances

⁵ It is possible that other FDCs could have been described as “co-led”; however, the survey did not request this information directly. The cases reported here are those where the respondent specifically stipulated the FDC was co-led.

OTD REQUESTING PRACTICE OBSERVED: CONTENT & CONDUCT

2. Were the elements of the specialised communication training observed in practice?

Meeting 1: Understanding Death

The family raised the issue of donation in the meeting about death in almost one-third of cases where data was available (29.4%, 40 cases of 136 cases). When family raised donation, in the majority of cases where responses were provided respondents thought that discussion about OTD was “sensitively deferred” (70.3% - 26 of 37 cases). All cases proceeded to an FDC.⁶

There was strong agreement that conversations had the following elements:

- Family members were encouraged to ask questions (93.3% - 126 of 135 cases)
- Brain death (or the futility of treatment) was explained clearly to family members (88.8% - 119 of 134 cases)
- Common language and phrases were used (80.9% - 110 of 136 cases).

There was strong agreement that family members had understood that their loved one had died or that treatment was to be withdrawn in the expectation of death (85.5% - 112 of 131 cases).

Meeting 2: Team Planning Meeting

In general, staff present reported that the Team Planning Meeting was conducted with a positive communication style.

The topics that were very frequently discussed (90%+) were:

- Clinical picture of the potential donor (97.2% - 138 of 142 cases)
- Family dynamics and background (94.9% - 131 of 138 cases)
- Outcomes of previous family meetings (90.5% - 124 of 137 cases)
- Planning about location for the Family Donation Conversation (90.5% - 124 of 137 cases)

Other topics discussed frequently (80%+) were:

- Decisions about roles for the FDC (87.3% - 117 of 134 cases)
- Discussion about who will raise OTD and how (87.0% - 120 of 138 cases)
- Australian Organ Donor Register (AODR) status of the potential donor (81.6% - 111 of 136 cases)

Meeting 3: Family Donation Conversation

Staff described the process around the FDC including the communication style adopted in the meeting in very positive terms in general. Nearly all staff providing feedback agreed that the FDC reflected elements of the specialised communication training, including:

- Family members were encouraged to ask questions (99.4% - 166 of 167 cases)
- The requester gave feedback to indicate they understood the family’s views during the conversation (98.8% - 165 of 167 cases)
- Common language and phrases were used (98.8% - 164 of 166)
- The requester established a rapport with family (98.8% - 165 of 167 cases)

⁶ Of the 11 cases where respondents reported the discussion was not sensitively deferred, 5 cases reported that there was a gap between meetings, 4 cases reported that there was no gap (suggesting the model was implemented flexibly according to the particular circumstances of the cases/ family preferences and the FDC discussion was held straight away), and no response was provided in 2 cases.

- The requester managed the emotions expressed by the family in a confident and competent way (98.8% - 164 of 166 cases)
- The requester left silences to allow family members time to process information (98.2% - 163 of 166 cases)
- The requester used open-ended questions (questions that require more than a yes or no response) (98.2% - 161 of 164 cases)

Topics were reportedly discussed to varying degrees in each of the FDCs:

- The decision is the family's to make (95.1% - 155 of 163 cases)
- Donation helps others (91.1% - 144 of 158 cases)
- Donation is an infrequent event (73.1% - 117 of 160 cases)
- There is a need for organs to be donated and why (62.6% - 97 of 155 cases)
- Many families have reported that they felt helped in their grief by their decision to donate (59.3% - 89 of 150 cases).

There were significant relationships between topics discussed during the FDC and consent to donate, with the following topics more likely to have been discussed where the decision was to donate: "Many families have reported feeling helped in their grief by their decision to donate" (69.6% - 64 of 92 cases where families consented to donation discussed this topic); "Donation is an infrequent event" (83.7% - 82 of 98 consenting cases discussed this topic); "There is a need for organs to be donated and why" (70.2% - 66 of 94 consenting cases) and "Donation helps other people" (95.9% - 94 of 98 consenting cases). There was not a significant association between consent rate and whether or not "The decision is the family's to make" was discussed (95% - 95 of 100 cases discussed this topic where the outcome was consent): this topic was reportedly discussed in the majority of cases, irrespective of donation decision (95.0% consent cf. 94.5% decline). There were significantly more topics discussed overall where the family consented (4 topics compared with 3 from a list provided to respondents).

Conclusion – OTD requesting practice observed: content and conduct

Based on reports from multiple observers, practice was consistent with the CRM in the majority of cases. The content of, and communication style adopted in the three meetings were aligned with FDC training.

STAFF TRAINING AND FDC EXPERIENCE

3. Did trained requesters feel that the specialised communication training has equipped them with the required skills to discuss donation with the family?

In general, participants in the FDCs reported that training had helped them, particularly the FDC Core Workshop (89.9% - 116 of 129 cases) and FDC Practical Workshop (91.0% - 111 of 122 cases).

Most staff agreed that their role was clearly defined in the Team Planning Meeting before the conversation (94.1% - 143 of 152 cases), and that the process leading up to and including the FDC felt like a team approach (96.1% - 148 of 154 cases). Staff who took part in FDCs reported they were "comfortable" with their performance in their particular role in the FDC (98.0% - 150 of 153 cases).

Views about some of the elements of potential models for requesting varied among those participating in the FDC, particularly in relation to whether the Treating Clinical Specialist should remain in the room during the FDC or leave the room.

Conclusion – Staff training and FDC experience

Staff taking part in FDCs consistently agreed that training helped them to fulfill their role and supported them to feel comfortable with their performance in their particular role in the FDC.

STAFF PERCEPTIONS OF THE FAMILIES' EXPERIENCE

4. Was the model effective in providing sufficient information to families/ next-of-kin to support decision making?

Staff involved believed that the FDC was effective in supporting families and that families and next of kin were provided with relevant information to support their decision – whether they consented or declined organ donation.

- Most staff who completed Tool 3 reported that the family received sufficient and appropriate information in the majority of cases (97.0% - 161 of 166 cases) and that the family were supported by staff during the conversation (99.4% - 167 of 168 cases). In most cases, staff disagreed (97.6% - 163 of 167 cases) that the family felt pressured to agree to OTD.

ASSOCIATION BETWEEN FDC PRACTICE AND CONSENT RATES

5. What was the impact of specialised communication training and elements of the different requesting model on organ donation consent rates?

Associations between FDC training and FDC outcome

As indicated above, completion of the Core FDC Workshop and the Practical FDC Workshop was a prerequisite requirement for the FDC Trained Requesters involved in the pilot.

- The presence of at least one FDC Trained Requester in Meeting 3 was associated with a higher consent rate: 69.3% (97 of 140 cases) compared with 45.2% where no FDC Trained Requester was present (19 of 42 cases).

Comparison of three groups leading the FDC reinforced the importance of training. There was a statistically significant difference in consent rates according to whether the person leading the FDC was trained or untrained and whether they were the Treating Clinical Specialist or not a member of the treating clinical team.

Donation Decision	Led by FDC Trained Requester (not Treating Clinical Specialist)	Led by FDC trained Treating Clinical Specialist	Led by Treating Clinical Specialist not FDC trained	Total
Agreed	70 74.5%	17 54.8%	19 45.2%	106 63.5%
Declined	24 25.5%	14 45.2%	23 54.8%	61 36.5%
Total	94 56.3%	31 18.6%	42 25.1%	167

Other factors associated with FDC outcome – prior decisions

There were a number of characteristics of the potential donor and/or their family/ next-of-kin that appeared to be associated with higher consent rates, probably because they provide an indication that a decision (or preliminary decision) had been made before the OTD requesting process commenced. In these

cases, and particularly in relation to being registered on the Australian Organ Donor Register (AODR), the prior decision was most likely to be consent. These variables can be considered as an indicator of “prior consent”. They are likely to be strong predictors of the outcome of the FDC.

- The patient was registered on the Australian Organ Donor Register (AODR) in 62 of 161 cases (38.5%)
 - When the patient was registered on the AODR (62 cases cf. to 96 cases not on AODR), the consent rate was 87.1% (54 of 62 cases) compared with 47.9% (46 of 96 cases) where they were not on the AODR
- The family knew correctly whether or not patient’s donation decisions were registered on AODR in 58 of 129 cases (45.0% of valid data)
 - When the family knew the AODR status of the patient (58 cases cf. to 69 cases), the consent rate was 84.5% (49 of 58 cases) compared with 53.6% (37 of 69 cases) where the family did not know the patient was registered on the AODR
- The family knew the patient’s donation decisions in 104 of 163 cases (63.8%)
 - The consent rate was higher where the patients’ donation decision were known (80.4% - 82 of 102 cases) compared with 36.2% (21 of 58 cases) when the family had not been aware of the patient’s donation decision
- The families raised donation before it was raised by health professionals in 40/136 cases (29.4%)
 - When the family raised donation before it was raised by health professionals, the consent rate was 89.7% (35 of 39 cases) compared with 51.1% (45 of 88 cases) where the health professional was the first to raise the topic of donation.

Associations between Collaborative Requesting Model (CRM) structure and Family Donation Conversation (FDC) outcome

Comparison of the consent rate for conversations categorised according to the presence of CRM structural elements provides some indication of whether or not the requesting practice affects the outcome of the FDC.

- Conversations with 3 meetings but no time gap between Meeting 1 and the FDC (40 cases) reached consent in 70.0% of cases (not differentiating the presence of an FDC-trained requester in the FDC)
 - In the cases where an FDC-trained person led the FDC the consent rate was 78.6%
- Conversations with 3 meetings and a gap between Meeting 1 and the FDC (118 cases) reached consent in 61.0% of cases (not differentiating the presence of an FDC-trained requester in the FDC)
 - In the cases where an FDC-trained person led the FDC the consent rate was 65.6%.

The relatively high rate of consent where there were three meetings, but no time gap between the conversation where family are informed the patient has died (or death is inevitable) and the FDC may reflect the influence of the family’s ‘prior decisions’ about OTD (based on either AODR registration or discussions prior to the current situation) on both structure and consent rate. For example, where the family is supportive of donation from the outset, and appears to have accepted death or the inevitability of it, there may be no need to have a formal gap between the discussion about death and the FDC discussion. Further analysis (using logistic regression) will explore the way in which FDC leadership and family knowledge of a person’s previously expressed intent to donate predict consent.

Conclusions

The evaluation demonstrated that there are a number of circumstances and characteristics that can affect the way OTD requesting proceeds, and the extent to which the elements of the CRM are observed. The

intent is that the elements of CRM are the default, and any variation from the model occurs only after deliberate consideration. The results demonstrated a general pattern that consent rates were higher where the FDC was led by an FDC-trained requester, regardless of the structure of the process. There was a significant association between the presence of an FDC-trained requester and consent rates when three meetings had been held. There was also 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, than an untrained Treating Clinical Specialist. The consent rate for FDCs led by a trained Treating Clinical Specialist fell between the two other groups.

LOCAL CONTEXT FOR OTD REQUESTING

6. Did the knowledge, attitudes and beliefs of Hospital Intensive Care and Emergency Department staff support donation?

The organisational environment in which OTD practice was being implemented was explored by capturing data pertaining to the knowledge, attitudes and beliefs of staff employed in participating hospitals' Emergency Departments (EDs) and Intensive Care Units (ICUs) prior to and after the monitoring of FDCs.

There were 1,043 respondents from ED and ICU across all hospitals at Time 1 (prior to the 12-month data collection period) and 786 at Time 2 (following 12 months of data collection). The response rate was difficult to calculate because of lack of accurate information about the distribution procedures in many cases. Based on available information, the estimated response rate at Time 1 was 22.5% (ranging from 10% to 37.1% at individual sites) and only 14.2% at Time 2, (ranging from 5% to 30%). The low response rate at Time 2 presents a limitation of the study; however the patterns in results were quite consistent across different respondent sub-groups.

Training

Overall, the majority of respondents reported receiving some kind of OTD-related training at both time points (77.5% (786 of 1014 cases) at Time 1 and 83.0% (580 of 699 cases) at Time 2), with wide variability across sites (ranging from 60.4% to 87.8% at Time 1 to 67% to 92.9% at Time 2). Fewer staff working in ED reported receiving training than staff in ICU. As would be expected, a much higher proportion of ICU Medical staff had attended the FDC Core Workshop than other respondents (at Time 2- 31.9% compared with 6.0% ICU Nursing; 3.8% ED Medical; 0.6% ED Nursing).

Knowledge, beliefs and attitudes

A series of questions explored the knowledge, beliefs and attitudes of staff. In general, the patterns of results suggested a reasonably supportive environment for requesting OTD at both time points, with the majority of staff agreeing they supported OTD in general. There was more ambivalence around some statements, including whether the costs of OTD are high compared to the benefits and whether the time and resources that go into OTD are excessive. Despite this, most of the views expressed were consistent with OTA policy and the recommended approach to FDC. There were consistent differences between medical and nursing staff and between staff from ICU and ED. In general, medical staff from ICU tended to have higher knowledge and more positive beliefs than nursing staff from EDs. Nursing staff from ICU and Medical staff from EDs tended to have levels of knowledge, beliefs and attitudes between these two groups.

Staff who had received FDC training (regardless of their role in the pilot) reported higher levels of knowledge, more positive attitudes and more confidence/skills to implement CRM-related practice than other hospital staff at both time points.

Roles and experience

The pattern of self-reported behaviour indicated that staff generally acted in a way that was consistent with their role. Those who were FDC-trained had significantly higher self-rated knowledge, skills and confidence to undertake a range of tasks associated with OTD process than those who were not trained at both time points. Those who were not FDC trained rated their knowledge, skills and confidence to use the Clinical Trigger that enables identification of a potential organ donor significantly higher at Time 2 than Time 1, but with some room for further improvement (56.7% - 373 of 657 cases) agreed moderately or strongly that they had the knowledge, skills and confidence to use the clinical trigger.

Conclusions

The results of the survey of hospital ED and ICU staff suggest that the context for implementing OTD in the pilot hospitals is generally positive. Overall, staff in participating hospitals were supportive of OTD at Time 1 and Time 2. There were some consistent patterns observed across department/profession categories.

There were some beliefs and behaviours that could be targeted for further discussion, particularly around behaviours that are relevant to the roles of staff across departments. There are some aspects of OTD policy and practice that all staff in ICU and ED are expected to know; for example, knowing how to use the Clinical Trigger to identify potential donors.

Overall, respondents believed their hospital “goes about organ donation” quite well or very well. The proportion rating it “very well” was higher at Time 2 than Time 1 (46.5% (295 of 635 cases) compared with 40.3% (335 of 832 cases) respectively.

CONCLUSION

The evaluation captured the complexity involved in the process of requesting organ and tissue donation. In most cases, several of the main features of the CRM were present: the opportunity for donation was generally raised with a potential donor family after the family understood the death or the inevitability of death of their family member; donation was raised by an FDC trained requester alone or in collaboration with the Treating Clinical Specialist; there was separation between these conversations; and a Team Planning Meeting was held (before or after the meeting at which death was discussed). Feedback from participants in the FDC indicated that the family was provided with factual information about organ and tissue donation and staff were generally satisfied with their role in the process. The data support a conclusion that information has been provided to families, which may help them to make an informed decision that they can be comfortable with in the long-term, regardless of whether their decision is to agree to or decline donation.

The data supported a conclusion that the specialised communication training was associated with higher consent rates. There was a significant association between the presence of an FDC-trained requester and consent. The pattern of consent rates according to who led the FDC indicated the rate was lowest where the conversation was led by a Treating Clinical Specialist who did not have specialist FDC training, with a higher rate where the FDC was led by an FDC-trained Treating Clinical Specialist, and the highest rate where the FDC was led by an FDC-trained requester who was not part of the treating clinical team. The likelihood of consent to donate was significantly higher if the FDC was led by a trained requester who was not part of the treating clinical team than a Treating Clinical Specialist with no specialist FDC training.

Evaluation Findings Summary

OVERARCHING CONCLUSION

The national evaluation of the pilot of models for requesting organ and tissue donation captured the complexity involved in the process of requesting organ and tissue donation. In most cases, several of the main features of the CRM were present: the opportunity for donation was generally raised with a potential donor family after the family understood the death or the inevitability of death of their family member; donation was raised by an FDC trained requester alone or in collaboration with the Treating Clinical Specialist; there was separation between these conversations; and a Team Planning Meeting was held (before or after the meeting at which death was discussed).

Feedback from participants in the FDC indicated that the family was provided with factual information about organ and tissue donation and staff were generally satisfied with their role in the process. The data support a conclusion that information has been provided to families. This may help them to make an informed decision that they can be comfortable with in the long-term, regardless of whether their decision is to agree to or decline donation.

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ORGAN AND TISSUE DONATION REQUESTING PRACTICE OBSERVED: STRUCTURE

1. Was the structure of the Collaborative Requesting Model (CRM) observed in practice?

In the majority of cases, the process followed was generally consistent with the FDC training. All three meetings took place in most cases (87.0% - 161 of 183 cases) and in more than two-thirds of cases (65.4% - 121 of 185 cases), all three meetings took place AND there was a gap between the meeting informing families about death and the conversation requesting donation. In 142 cases (80.7% of the total) an FDC-trained requester was present in the FDC meeting. The data indicated that, in general, the meetings were held in a manner that was consistent with FDC training. That is:

- the majority of cases reflected the key structural elements of the CRM
- there was evidence of conscious flexibility in implementation of the CRM, generally with the intent to better support families' needs in specific circumstances

ORGAN AND TISSUE DONATION REQUESTING PRACTICE OBSERVED: CONTENT & CONDUCT

2. Were the elements of the specialised communication training observed in practice?

Based on reports from multiple observers, practice was consistent with the CRM in the majority of cases. The content of, and communication style adopted in the three meetings were aligned with FDC training.

STAFF TRAINING AND FDC EXPERIENCE

3. Did trained requesters feel that the specialised communication training has equipped them with the required skills to discuss donation with the family?

Staff taking part in FDCs reported that the FDC Core Workshop and Practical Workshop they attended helped them to fulfil their role (89.9% - 116 of 129 cases and 91.0% – 111 of 122 cases respectively), and that they were “comfortable” with their performance in their particular role in the FDC (98.0% - 150 of 153 cases).

STAFF PERCEPTIONS OF THE FAMILIES’ EXPERIENCE

4. Was the model effective in providing sufficient information to families/ next-of-kin to support decision making?

Most staff who completed Tool 3 reported that the family received sufficient and appropriate information in the majority of cases (97.0% - 161 of 166 cases) and that the family were supported by the staff during the conversation (99.4% - 167 of 168 cases). In most cases, staff disagreed (97.6% - 163 of 167 cases) that the family felt pressured to agree to OTD.

ASSOCIATION BETWEEN FDC PRACTICE AND CONSENT RATES

5. What was the impact of specialised communication training and elements of the different requesting model on organ donation consent rates?

The evaluation demonstrated that there are a number of circumstances and characteristics that can affect the way OTD requesting proceeds, and the extent to which the elements of the CRM are observed. The intent is that the elements of the CRM are the default, and any variation from the model occurs only after deliberate consideration. Importantly, regardless of the structure of the requesting process, the presence of an FDC-trained requester who was not a member of the treating clinical team was associated with higher consent rates.

LOCAL CONTEXT FOR OTD REQUESTING

6. Did the knowledge, attitudes and beliefs of Hospital Intensive Care and Emergency Department staff support donation?

The results of the survey of hospital ED and ICU staff suggest that the context for implementing OTD in the pilot hospitals is generally positive. Overall, staff in participating hospitals were supportive of OTD at Time 1 and Time 2. There were some consistent patterns are observed across department/profession categories

There were some beliefs and behaviours that could be targeted for further discussion, particularly around behaviours that are relevant to the roles of staff across departments. There are some aspects of OTD policy and practice that all staff in ICU and ED are expected to know; for example, knowing how to use the Clinical Trigger to identify potential donors.

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