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Families' reflections on the process of brain donation following coronial autopsy

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Abstract

This study aims to explore families' reflections on their decision to donate brain tissue to the NSW Tissue Resource Centre (NSW TRC), Australia. Specifically, the study aims to investigate respondents' initial reactions to the request for donation, primary reasons for their decision, and subsequent satisfaction levels. Participants were next-of-kin (NOK) contacted between May 2002 and May 2008, on the day of their relative's autopsy, who agreed to donate brain tissue to the NSW TRC for medical research. All 111 NOK were invited to participate, and those who agreed completed an anonymous questionnaire. Fifty completed questionnaires were received. Results showed that 74% of respondents were not upset by the donation call and 98% were satisfied with their decision to donate. Of the 22% who reported having been upset, many indicated that their distress was partly related to their circumstances. When asked the main reason for their donation, 66% had wanted to help others, or help research, while 24% stated their primary reason as a belief that they were respecting the wishes of their deceased relative. These findings show that NOK are not further distressed by being asked to donate brain tissue, give altruistic reasons for consent and are satisfied with the decision they made. In both this study and previous literature, the importance of discussion about organ donation amongst relatives is a recurring theme. Knowledge about a relative's wishes is likely to help facilitate decision-making, overcoming at least one crucial barrier to lifting rates of organ donation for transplantation and research.

Keywords

Organ; Brain; Donation; Coronial; Distress; Satisfaction

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Introduction

Post-mortem human brain donation allows research to be conducted on many aspects of the human brain in health and disease. While advances in animal modelling and medical imaging can assist in our understanding of the brain's structure and function, only through donation of the whole human brain can neurochemical, proteomic, neuropathological and even genetic differences be examined. An important aspect of this however, is the concept of donating one's brain after death.

The New South Wales Tissue Resource Centre (NSW TRC) was established in 1994 to collect, characterise, store and distribute central nervous system tissue to Australian and international researchers studying disorders of the brain including alcohol-related brain damage, and psychiatric illnesses such as schizophrenia and bipolar disorder. The NSW TRC collects these tissues in two ways; (1) through prospective brain donor programs where members of the community are invited to give consent to donate their brain for research; and (2) through a telephone call to the next-of-kin (NOK) of deceased persons on the day of autopsy, where the NOK is asked to consider donating his or her relative's brain for medical research (NSW Tissue Resource Centre 2009).

The current protocol for obtaining consent from families by telephone was commenced in May 2002. Results from a recent study showed that 54% of NOK contacted during the first 5 years of this protocol consented to donate their deceased relative's brain (Garrick et al. 2009). The two modal reasons volunteered by participants for brain donation in this study were, 'to help others' and consideration of the wishes of the deceased. Both altruism and knowledge of the prior wishes of the deceased are frequently mentioned as key motivating factors in the transplant and research organ donation literature (Beard et al. 2002; Bennett and Savani 2004; Glaw et al. 2009). Informal observation at the time indicated that NOK were not further distressed by the call asking them to consider brain donation. In fact, several families acknowledged the importance of the donation offer and expressed appreciation for the opportunity to donate (Garrick et al. 2009).

Similar results were shown by Azizi et al. (2006) using data from the first year NSW TRC cohort (May 2002–May 2003). Azizi and colleagues suggested that their study could have been enhanced if NOK were contacted for follow-up 6 months after initial contact (Azizi et al. 2006).

In support of these findings, an exploratory study by Millar et al. (2007) found that bereaving families do not experience further distress when being approached to donate brain tissue for medical research, and that relatives who agree to donate do not subsequently regret their decision. Millar et al. (2007) also found that six of the seven families who responded to their questionnaire firmly believed that all bereaved families should be offered the opportunity of donating for research, as their right, and that none had felt pressured into making a donation.

Analogous observations have been made by researchers within the organ donation for transplant literature, who have noted that relatives who agree to organ donation do not regret their decision, and in fact, many derive comfort from the knowledge that their decision has helped others (Floden et al. 2006; Ormrod et al. 2005).

These results contrast with the large body of literature that attempts to explain low organ donation for transplant rates, pointing to the discomfort or distress experienced by medical professionals in approaching families for organ donation as one factor for the low rate, due to fears of adding to the burden of grieving families (Bellali et al. 2007; Sque et al. 2000; Wakeford and Stepney 1989). Wakeford and Stepney (1989) found that the main factor restricting organ harvest in intensive care units was staff dislike of adding to relatives' distress, followed by inadequate training in approaching relatives and negative media publicity. Similarly Regehr et al. (2004) noted that the process of organ procurement was stressful for nurses, resulted in personal feelings of distress and negative attitudes to organ donation, which may in turn be projected to others, ultimately undermining efforts to procure organs. Although there is much speculation about the discomfort bereaved relatives may (or may not) experience when asked to donate organs, few researchers have empirically examined the personal impact of such approaches, particularly in the context of brain donation for research.

This study aims to explore families' reflections of their decision to donate brain tissue, through a follow-up questionnaire to those NOK who consented to donate their relative's brain to the NSW Tissue Resource Centre (NSW TRC) during the six-year period from May 2002 to May 2008. The study aims to elucidate respondents' recollection of their initial reaction to the request, whether consultation occurred, the main reason for consenting to the donation, and whether they are currently satisfied with their decision. Based on previous research, we predict that most NOK will give an altruistic reason for their donation, will indicate satisfaction with their decision to donate and will not report additional distress from the donation call.

In broader terms, this project aims to further our understanding of families' motivation to donate brain tissue for medical research and to potentially help improve NSW TRC processes regarding the approach to next-of-kin to request brain donation. The results of this research may ultimately improve donation rates.

Materials and methods

Subjects

Potential participants were all one hundred and eleven NOK who had consented to donate their relative's brain to the NSW TRC within the 6-year period from 17th May 2002 to 17th May 2008. These donors (and their NOK details) were sourced from the Department of Forensic Medicine (DOFM) in Sydney, Australia. NOK were originally contacted by telephone on the morning of their relative's coronial autopsy and verbal consent for donation of the brain for research was recorded. The procedure for these calls has previously been described (Azizi et al. 2006; Garrick et al. 2009).

It is important to note that the present study only included those who were 'cold called' on the day of autopsy. NOK who had approached either DOFM, the NSW Coroner's Court or the NSW TRC to offer donation of tissue were not included. Similarly, NOK who had been approached for donation and had declined consent were not surveyed, as contact details of these families had been destroyed in accordance with NSW TRC ethics protocol. Approval for the current project was granted by the Human Research Ethics Committees of the Sydney South West Area Health Service and The University of Sydney.

Questionnaire design

A 24-item questionnaire designed to ascertain NOK reflections on the process of brain donation was developed using themes from the literature, and from previous research using early populations of the current cohort (Azizi et al. 2006; Garrick et al. 2009). The content of the current questionnaire was modelled on a questionnaire used in a recent NSW TRC study to ascertain motivation for brain donation by pre-consenting potential brain donors (Glaw et al. 2009), and on the Edinburgh Sudden Death Brain and Tissue Bank Questionnaire for Families (Millar et al. 2007). Our questionnaire contained two parts. Part 1 consisted of items such as the NOK's initial reaction to the request for brain donation, whether he or she was upset by it, whether consultation occurred, if the respondent felt pressured into making (or not making) a donation, whether he or she was satisfied with the decision, and the reasons for the donation. Most of these items consisted of ‘yes’ and ‘no’ checkboxes with space provided to write additional comments. The questions assessing participants’ feelings and initial reaction to the call, as well as reasons for the donation decision were open-ended to allow participants to describe their responses in their own words. Part 2 consisted of demographic items; i.e. participants’ age, gender, occupation, partnership status, religion, education, ethnicity and country of birth. Respondents were given checkboxes for each of these items, apart from ‘country of birth’ for which a space was provided.

Questionnaire distribution

In February 2009, all potential participants (one hundred and eleven NOK) were mailed a one-page information statement and five-page questionnaire inviting them to participate in the study. NOK who agreed, completed the anonymous questionnaire and returned it in a stamped, addressed envelope provided to them. A follow-up letter was sent to all NOK approximately 3 weeks later, reminding them to return their questionnaires. The final completed questionnaire was received in May 2009.

Data analysis

This study is primarily qualitative in design. Individual descriptive expressions were identified and recurrent themes were drawn. Participants’ original responses were compared with these themes to ensure a high degree of concordance. Themes were analysed using SPSS version 11.5.

Results

Questionnaire responses

Eleven questionnaires were returned as undeliverable and 50 completed questionnaires were received (50% of those potentially delivered). The response rate for this study was similar to that for a recent mail survey of registered brain donors to our Centre (53%; Glaw et al. 2009).

A further five blank (opened) questionnaires were returned from NOK who had decided not to participate. One of these was accompanied by a note stating, ‘I’m very sorry, but I just don’t feel up to doing this at this time.’ One NOK who returned a blank questionnaire requested no further contact. Another telephoned to say that she had received counselling following the donor’s death and felt that receiving our mail was distressing. She also requested no further contact.

Surprisingly we received two calls from people who could not recall consenting to brain donation. One father could recall neither the phone call we had made on the day of his son’s autopsy, nor the subsequent written consent paperwork (although a completed copy had been returned to us by him). The verbal recording of his consent was replayed, and he was reassured that it was entirely optional to complete the questionnaire. The second call was received from a NOK who was unable to recall donating his sister’s brain tissue to our centre. He was also reassured of the validity of the donation and that it was optional to complete the questionnaire.

One consenting NOK had pre-deceased our survey and her immediate family completed the questionnaire on her behalf, taking into account discussions they had with her at the time of the donation call. Questions were completed according to the family's perceptions of how the NOK had felt about the call. These responses were included in our analysis.

The questionnaire also prompted several calls and additional written responses from NOK who wished to update their contact details, discuss issues such as mental illness and their deceased relative, or find out more about the donation/research process. One NOK expressed a willingness to complete further surveys.

Demographics

Thirty-one of the respondents (62%) were female and 19 (38%) were male, consistent with the gender ratio of the population sent the questionnaire. Respondents' age distribution is shown in Table 1, along with partnership status and NOK relationship to the deceased. As shown, the majority of respondents were aged between 45 and 74. Most were married or widowed.

Table 2 shows participants' education levels and main occupation type. Sixty-eight percent of respondents had reached a secondary or certificate level of education as their highest qualification, and over onethird were trained professionals.

Country of birth, ethnic background and religious affiliations are shown in Table 3. All respondents were born in Australia or Europe and at least 96% were Caucasian (4% gave no response to this item). Almost two-thirds were Christian.

On average, 46.6 months (SD = 24.4 months) had passed since the NOK's donor relative had died (range = 11–96 months). Two NOK gave no response to this question.

Time taken to complete the questionnaire ranged from 5 to 60 min, with a median time of 10 min.

Feelings about being approached to consider brain donation

Not all respondents described their actual response to the call but instead outlined their overall mood relating to their relative's death, or commented on the manner of the caller. Modal responses were surprise (20%), shock (20%) and feeling 'ok' (14%). For ease of reporting, responses were categorised into positive, negative and neutral emotions. These are displayed in Table 4. Some respondents described feelings in more than one of these groups and these have been scored in both categories.

Many participants also commented on their situation, expressing shock or sadness at their sudden loss, but hoping that something good could come of their relative's death. Two said that they were surprised about receiving a donation request for brain tissue versus other organs or tissues. One was concerned about putting the caller at ease, and one commented that she was pleased, as her husband had, 'wanted to donate organs but none other could be used'. Another displayed a remarkable degree of objectivity stating, 'any worthwhile use of corpses is fine by me'.

Distress from the call

Respondents were asked if they could remember whether the donation call had upset them. Their responses are presented in Table 5.

As shown, almost three quarters reported not being upset by the call. Of the 22% who were upset, two clarified that this was their initial response. Another reflected, 'It meant he was really dead'. One NOK said that the call was, '…something I had not expected'. Another added that she was upset, 'not because it was going to happen, just because of circumstances'. Six NOK did not provide explanation as to why the call was upsetting to them, beyond their initial response to how they felt about the telephone call. Of the two who said, 'yes and no', one referred us to the first question where she had stated she was shocked, and commented that her relative had died suddenly.

Initial reaction to request for brain donation

Some participants' responses to this item fit more than one category. The response deemed to best represent a respondent's initial reaction was selected. Results are shown in Table 6.

The largest group, nineteen NOK (38%), gave altruism as their initial reaction to the request for brain donation, indicating that they thought the donation could help others, or help research. One indicated that she found the donation question unexpected and was overwhelmed by it, saying, 'I had just hung up the phone from the coroner's office, saying they didn't know how he died and I had to wait weeks. I couldn't think properly.' Another said she was waiting on confirmation that her deceased relative's autopsy had been conducted, so that a date for the funeral could be arranged. In that context the request to keep the brain tissue for research was described as more of a relief than a shock.

Consultation prior to decision-making

Twenty-five respondents (50%) reported they did not consult with anyone else prior to making their decision to donate. Of the 25 who consulted, all had discussed their decision with immediate family members. Two of these also consulted with extended family (sister-in-law/cousin).

Sensitivity of caller

The majority of NOK (90%) felt that they had been approached in a sensitive manner. Disappointingly, five (10%) did not feel they had been approached sensitively.

Influence of others

Forty-seven NOK (94%) responded that they had not felt pressured to either accept or decline the donation offer. One said she had felt pressured to donate by the caller, indicating later in the questionnaire that more time to decide on the question of brain donation would be preferable. Another respondent who had said, 'yes and no' to the question of whether she had felt pressured into donation, said she understood the need for a quick decision, indicating that it was the short time frame for the decision that contributed to her feeling of pressure. One said she had felt pressured by the rest of the family into declining the donation offer, but nevertheless had agreed to donate.

Concerns from family

Ninety-two percent of NOK indicated that there were no concerns raised amongst family members following the donation. Four (8%) said that concerns were raised. One specified that concerns were raised by her husband's sister. Another stated that he had found his sister's will following the donation, which indicated that she did not wish to be an organ donor. The family had subsequently reversed the donation as a result of this information and the brain was returned for the funeral. Another NOK said that the concerns raised by family members following the donation were that, 'he wouldn't be complete for the funeral'. The NOK who had initially been pressured by the rest of the family into declining the donation offer (see above), said, 'they weren't [subsequently] happy with me making the decision'.

Opportunity to ask questions

Forty-two NOK (84%) responded that they recalled having had a chance to ask questions during their initial contact with us. Seven (14%) said they did not have a chance to ask questions, and one did not answer the question, however commented that there may have been questions but he had never thought about it.

Suggestions for improvements to the call process

When asked if anything may have been done better at the time of initial contact, 14% said, ‘yes’ and 86% said, ‘no’. Of those who responded, ‘yes’, comments centred around the idea that the call came ‘so soon’ after the death and that it was a shock. Several NOK said they would have liked more time to make decisions. Two respondents stated they would have liked more information about the benefits of donating or about the research itself.

Satisfaction with the decision

Respondents were asked whether they feel satisfied with the brain donation decision they made. Forty-nine (98%) said, ‘yes’ and only one (2%) said, ‘no’. Of those who were satisfied, 27 provided further information about why they were satisfied. Most gave altruistic reasons such as being glad their relative’s death could help others. One said, ‘happy to help others. Nice to know his premature death had a positive outcome’. Another said she was, ‘glad to help research, especially since my husband’s death was due to suicide’. Several believed it was what their relative would have wanted. One said, ‘it was the right decision’. Even the NOK who had reversed his decision felt satisfied, however wished he had found the will earlier. The sole respondent who was unsatisfied with having donated commented, ‘I just feel awful about giving away his brain’.

Reason for donation decision

The main reasons offered by NOK for their decision to donate brain tissue are presented in Table 7. Two-thirds (66%) indicated that they had wanted to help others, or help research. Almost a quarter (24%) commented that they had decided to donate because they were either aware that their deceased relative had wanted to be an organ donor, or believed it was something he or she would have wanted. For example, one NOK said, ‘My sister always thought of others before herself so I am sure it would have been the correct decision’. Another said, ‘It was my husband’s wishes to have his organs donated. He would have been pleased that I felt I did what he wanted’.

Prior discussion about organ donation

NOK were asked whether they had discussed organ donation with their donor relative prior to his or her death. Responses are shown in Table 8. Eighteen NOK provided additional comments for this item, with four noting that the deceased had indicated consent for organ donation on his or her driver’s licence. Three stated that the whole family agreed with organ donation, and one said it had first been discussed approximately 20 years before the donor’s death, and at regular intervals thereafter.

Prior consent for donation of own organs

In NSW there are two main avenues to pre-register consent to donate organs: (1) via the Australian Organ Donor Register; and (2) via a NSW driver’s licence (NSW Department of Health 2010).

When asked if respondents had pre-registered consent to donating their own organs or tissues for transplantation or research purposes prior to their donor relative’s death, 29 (58%) said, ‘no’ and 20 (40%) said, ‘yes’. One gave no response. Those who replied, ‘yes’ were asked to specify with whom they had registered their consent. Thirteen (26%) indicated that they had consented to organ donation prior to their relative's death via their driver's licence. One simply said, 'yes, for transplant purposes'. Six who responded, 'yes' did not specify which agency they had consented with and two who had not consented made additional comments. One said, 'I intend to do so' and another said, 'I feel I am too old to be of use'.

Opportunity for all families to donate

Respondents were asked if they thought the opportunity to donate tissue/organs for research should be offered to all families. Forty-four (88%) said, 'yes', three (6%) gave no response, two (4%) said, 'no' and one was unsure. No additional comments were made for this item.

General comments received

Half of the respondents chose to write additional comments. Many were complimentary about the donation process, or wished us well with the research. One said, 'I was treated with the utmost respect, and felt my husband's remains were also treated with respect and dignity. My only request was that he appeared 'untouched' in the open coffin, which he indeed did and I'm grateful for that'. Another said, 'I thought the process was handled with kindness and dignity'. One stated their relative was, 'an intelligent and talented person who was loved by his family and friends. Mental illness robbed him of a normal life. Anything that can be done to prevent others from suffering as he did is a good thing'. Two had helpful suggestions, saying, 'I thank you for your work and wish you well. I often think if free cremation was offered, perhaps more people would donate organs', and, 'I believe that when anyone donates, as my family has done, I think a certificate of recognition should be sent to the next of kin, or some form of appreciation, explaining what the donation is used for.' Several other NOK requested further information about the research or its results.

Discussion

One of the key objectives of this study was to examine the responses of NOK to the donation call, to ascertain whether additional distress was caused, with the aim of improving our call technique. While 40% of respondents were initially surprised or shocked by the call, the majority of respondents were either not upset by it, or their distress was partly a reaction to the circumstances they were in, as all were coming to terms with the sudden death or suicide of their relative. This finding supports our hypothesis that the majority of families are not further distressed by the call, and is in concordance with previous research showing that families were not further upset by an approach for brain donation, despite the proximity to their bereavement (Azizi et al. 2006; Garrick et al. 2009; Millar et al. 2007).

The literature has described reluctance or even distress experienced by nurses and other medical professionals in approaching families for transplant donations, due to fears that this will add to bereaving relatives' burden (Floden et al. 2006). Such reluctance has been postulated as one reason for the low organ donation rates experienced in many countries. The donation call made by members of the NSW TRC is conducted in a very sensitive manner, and whilst often an anxiety provoking experience for the caller, it is one that is extremely rewarding. Indeed, our survey showed that some NOK were concerned at putting the caller at ease, even during a time of such personal upheaval. From the authors' experience, it is not unusual for NOK to express consideration for the feelings of the caller and to attempt to provide reassurance that the donation approach is not an adverse experience. This was also noted by Azizi et al. (2006).

In terms of consultation with others, only half the respondents reported having consulted with immediate or extended family prior to making their decision, indicating that a surprising number were confident in making the decision themselves, or did not wish to involve others. Only a few respondents reported feeling pressured in their decision-making, with several recognising that there were unavoidable time pressures involved. Similar findings were reported by Millar et al. (2007).

Following the donation process, only four NOK reported concerns raised by family, suggesting that most families were comfortable with the decision made. This is reassuring, given the fact that most NOK had a maximum of only 1 or 2 h to consider the donation question and make their decision. Also reassuring, is that the vast majority of respondents felt that they had been sensitively approached by the caller.

Research conducted within the transplant domain suggests that families who have previously discussed organ donation with their relatives and are aware of their wishes are more likely to donate (Beard et al. 2002; Radecki and Jaccard 1997; Siminoff et al. 2001; West and Burr 2002). Conversely, several studies have found that families who are unsure of their deceased relative’s wishes are likely to refuse consent to donation (West and Burr 2002). While surveys show that as many as 90% of Australians support organ donation, one-third have never discussed their donation wishes with their family. Forty percent are unaware that their family is asked to make the final decision about donation (Australian Government Organ and Tissue Authority 2009). In the current study, less than half of our respondents (44%) reported having discussed the concept of organ donation (in general) with their deceased relative prior to his or her death. Consistent with previous literature, however, almost a quarter of all respondents cited prior knowledge of the deceased’s intent to be an organ donor [for transplant], or a belief that he or she ‘would have wanted to donate’, as their primary reason for giving consent to brain donation (Garrick et al. 2009).

In a survey of elderly pre-consented brain donors, Stevens (1998) found that the relatives of these donors considered it important to honour their parent’s or spouse’s wishes, even when they were not greatly disposed to the idea of brain donation themselves. Among the families of pre-consented donors, none had refused consent at the time of their relative’s death. The desire to honour or fulfil the wishes of a deceased relative is a common motivating theme for consent within the organ donation literature (Sade 1999; Stevens 1998).

Bennett and Savani (2004) noted that offering the opportunity to donate offers a person the chance to assert altruism. Two-thirds of our participants stated that they wished to help others or support research. Similar motives were given in Stevens’ (1998) study, whose participants stated that their main reason for agreeing to donate brain tissue was to help others or help research. Intangible benefits such as positive feelings from contributing to the good of society and respecting a relative’s prior wishes have been well documented in both research and transplant donation literature (Azizi et al. 2006; Garrick et al. 2009; Sade 1999).

Australia has a world-class reputation for successful organ transplantation, despite one of the lowest organ donation rates in the developed world. In 2009 there were 11.3 donors per million people in Australia, a rate half that of the USA and three quarters that of the UK (Van Gelder et al. 2010). Only one-third of the demand for organ transplants in Australia is currently being met (Australian Government Organ and Tissue Authority 2009).

In a recent study of pre-consenting, registered brain donors from our Centre by Glaw et al. (2009), 81% of respondents reported they had also registered to donate organs for the purpose of transplantation. The majority of respondents in the Glaw et al. (2009) study had indicated this through their driver’s licence. A study of nurses’ attitudes towards cadaveric donotransplantation by Sque et al. (2000) found that perceived knowledge about organ donation increased positive attitudes towards the process. In our study, we wished to identify how many NOK had pre-consented to donating their own organs for transplantation or research prior to the call, as this may have influenced their response to our call. We found that only 40% of NOK had done so. The difference between the Glaw et al. (2009) study and ours, is that the former was of people who had pre-registered consent to donate their brain, so it is not surprising that these individuals had also registered for organ donation in general.

Pleasingly, almost all of our respondents expressed satisfaction with their decision to donate. Most who expanded on their response gave altruistic reasons, or indicated they were satisfied because they believed it was what the deceased would have wanted. These responses were clearly in keeping with the reasons that most NOK gave for their donation, and support our hypothesis that NOK would be satisfied with their decision. Millar et al. (2007) also found that all respondents in their study were satisfied with the decision they had made at the time of brain donation. Importantly, most families in both studies believed that the opportunity to donate tissues or organs for research should be offered to all families.

NOK were also asked whether they had an opportunity to ask questions during the call, and for suggestions for improvements to the process. Fourteen percent stated they did not have an opportunity to ask questions. A consideration for the future, may be for callers to formally check whether NOK have any questions or further comments, as this is not currently routine.

The majority of NOK had no suggestions for improvements to how the initial contact was handled, indicating a high degree of satisfaction. Of those who did suggest improvements, several commented that they would have liked more time to make their decision. Previous research at our Centre shows that the more time that elapses between the deceased's death and the donation call, the more likely NOK are to consent (Garrick et al. 2009). West and Burr's (2002) research within the transplant domain, also highlights the fact that the timing of the request influences consent rates. Families need time to come to terms with the death of their relative before being approached about donation of organs or tissues. Inappropriate timing (for example informing the family of their relative's death and immediately requesting donation) tends to result in consent being denied (West and Burr 2002). Those contacted by our Centre during their relative's autopsy are almost always required to make their decision within a 1–2 h period from 9 am, a time-frame dictated by the post-mortem examination itself. Ideally we would like to allow more time for families to make their decision, however this is beyond our control. Fortunately most families are understanding about the time constraints, and results indicate that nearly all are satisfied with both the contact they have had with us, and their decision to donate.

One suggestion for improvement came from two respondents requesting more information about the benefits of the donation or about the research itself. The introduction to our call is scripted to comply with the NSW Human Tissue Act (1983). Following this, the NOK's response to our request for brain donation determines the direction the call takes, and we answer any questions that arise. Research is not routinely discussed in any depth during this call unless requested, as we do not wish to overwhelm NOK with unnecessary information at that time. To address the request for more information, we have sought ethics committee approval for a new information statement/brochure to be mailed to all families who agree to donate, together with our consent form and cover letter. This brochure provides more information about the NSW TRC and the research it facilitates than was previously available —and is sent in a written format that can be absorbed in the NOK's own time.

At the conclusion of the questionnaire, many respondents added their own comments. Many were complimentary, and a few explicitly stated that they felt they had been treated with respect, and that the process was handled with kindness and dignity. One NOK commented that if free cremation were offered perhaps more people would donate organs. Although such incentives are beyond the scope of our Centre, the idea of offering financial or material reward for donation has previously been considered by various authorities. In 1999 the US state of Pennsylvania planned to introduce $300 rebates towards funeral expenses for people whose organs were used for transplantation. Due to concerns relating to whether the stipend would violate federal laws that prohibit offering ‘valuable consideration’ in exchange for organs, reimbursements were instead directed towards accommodation and food expenses for donors or their families (Charatan 1999; Snowbeck 2002). Healthcare authorities in a number of countries have similarly considered material incentives to boost organ donation rates, although in Britain and Australia it is also considered an offence to purchase or sell body parts (Bennett and Savani 2004; George 2005).

One NOK recommended that we send a certificate of recognition, accompanied by an explanation of what the donation is used for. While the NSW TRC is prevented from giving individual research results to families, we can provide general information about the research undertaken, and this is our aim with the new information statement. The statement will be sent to all future NOK who consent to donate, and also those who were mailed this study’s questionnaire, as part of a follow-up communication.

Within the context of incentives to increase organ donation rates, Bennett and Savani (2004) noted that organ donation ‘breaks the socio-cultural norm of ‘gift exchange’ whereby gifting is typically associated with giving and receiving, leaving a psychological imbalance in the relationship.’ (p68). These authors noted that the provision of some form of overt recognition for donors (and their families) might assuage such feelings of imbalance or credit.

Each year around Australia, annual ecumenical thanksgiving services are held by various organisations such as the Lions NSW Eye Bank and the Australian Red Cross, in memory of those who have generously donated organs and tissues (Transplant Australia 2009). These services are for donor families, transplant recipients and other members of the community touched by organ donation (Australian Government Organ and Tissue Authority 2010; Lions NSW-ACT Save Sight Foundation 2009).

The NSW TRC is a small body with limited funding. While it was previously recommended that we contact families after 6 months to follow-up on their experience of brain donation (Azizi et al. 2006), for coronial autopsy cases, the general policy has been to limit additional contact with families, as further contact could be seen as an intrusion and reminder of a stressful period. A means of formal appreciation for donor families, such as a ‘Certificate of Appreciation’ sent to all next of kin in recognition of their generous donation, could however be investigated. A certificate would likely provide families a sense of acknowledgement, and reassurance that their donation is vital to research. According to Floden et al. (2006), follow-up of family after donation is important and might influence societal attitudes towards donation.

It is important to note that the cases under discussion are coroner’s cases where the NOK was coming to terms with a sudden, unexpected death in the family. There was little or no contact with NOK between the donation and survey. Some may have moved and a few may have died in the interim between donation and the questionnaire mail-out. Circumstances were generally stressful and distressing at the time of their relative’s death, making this a potentially difficult survey to complete for several families. Therefore, it was felt that it was inappropriate to contact NOK more than once to remind them about returning the questionnaire. Some families may also have had difficulty remembering details of the donation call, as up to 7 years had passed since their relative died, and several NOK would have been under considerable stress at the time. It is acknowledged that the accuracy of the responses given should be considered in light of this limitation. Taking all of these factors into account, although a 50% response rate may also be considered a limitation of the study, we consider it to be a very good response.

Another important limitation of this study is that we were unable to survey NOK who declined consent for brain donation, to ascertain their reaction to the request, whether they are now satisfied with their decision not to donate, and what their suggestions might have been to improve the process. While this may be possible in the future, it would require approval from relevant ethics committees to allow retention of the contact details of NOK who decline consent. Data from our five-year study indicate that those who declined consent gave reasons over the telephone at the time indicating discomfort with the thought of donation, consideration of the deceased’s and other relatives’ wishes and practical concerns such as insufficient time (Garrick et al. 2009). The chance to formally survey these NOK would provide valuable further insights.

Future research may also wish to examine whether the experience of being asked for consent to the donation of a relative’s brain for medical research had influenced NOK to consider signing up for organ donation for transplant or research themselves, subsequent to their contact with the NSW TRC. Our current survey enquired only whether NOK had consented to donating their own organs or tissues for transplantation or research purposes prior to their donor relative’s death.

Based on previous research and the results of the current study, potential future directions for the NSW TRC could include:

- Asking NOK whether they have any questions or comments as a formal and routine part of the donation call.
- Providing a ‘Certificate of Appreciation’ to all NOK for their generous gift.
- Sending families a more detailed information statement about the NSW TRC and its associated research.
- Routinely mailing each NOK our questionnaire 6 months after their donation whilst the donation call is easier to remember. This would enable the NSW TRC to continually monitor the satisfaction of NOK and incorporate suggestions for improvements to the process on a regular basis.

Another future goal might be to investigate the feasibility of including brain donation for research on the Australian Organ Donor Register. Including options for both research and transplant donation would likely increase public awareness of brain donation and result in more people donating brain tissue for research in Australia (Azizi et al. 2006). Such inclusions are unlikely to have a negative impact on consent for organ donation for transplant, as long as separate and specific written permission is sought for the use of donated organs and tissue for research, and the process of obtaining consent for research donation remains clear and transparent. Explicit written permission is currently already sought in Australia before donated organs and tissue can be used for medical research, however such permission is obtained through the relatively obscure means of contacting individual families after death.

In relation to organ donation for transplant, research has shown that two of the key issues hampering organ procurement are: (1) fear by medical staff of increasing relatives’ distress, and (2) a lack of training in the communication skills needed to approach families to request donation (Wakeford and Stepney 1989; Bellali et al. 2007). To address these (and other) issues, a number of researchers have suggested ways to facilitate the process of requesting organ donation by medical staff. These include:

- Providing medical professionals with good education and training in communication skills and ways to approach relatives for organ donation, as well as ensuring thorough professional knowledge and understanding of the issues involved in donation ([e.g. ‘brain death’; ‘donation after cardiac death’] Azizi et al. 2006; Floden et al. 2006; Stevens 1998; Wakeford and Stepney 1989; West and Burr 2002).
- Implementing standardised processes and procedures for facilitating organ donation (West and Burr 2002).
- Making cultural resources and contacts available to ensure that the family’s decision is congruent with their personal beliefs and values (West and Burr 2002).
- Using a joint approach by organ procurement coordinators and hospital staff members to request organ donation (West and Burr 2002).
- Incorporating discussion about organ donation into routine end-of-life care or using dedicated neutral third-party facilitators (Mandell et al. 2006).
- Developing specialist training programs for health professionals working in critical care (Bellali et al. 2007).

We believe that a range of measures are required to address the above named obstacles to organ procurement amongst medical staff. These may include the dissemination of research findings such as those in this study, to reassure medical professionals that families are not averse to being approached about organ donation, and to dispel fears surrounding this topic. In addition, workshops promoting best practice in ways to approach NOK would almost certainly be helpful, particularly where participants are engaged in practical, hands-on training (e.g. using role plays), in which communication skills can be developed and refined. Another strategy might be to pair newcomers with experienced staff who can act as mentors, demonstrating valuable communication skills and an appropriate manner to adopt when approaching families.

Our study shows that NOK do not suffer additional distress from the donation call, give altruistic reasons for consent and are satisfied with their decision to donate. In both this study and those of Azizi et al. (2006) and Garrick et al. (2009), the importance of prior discussion about organ donation among relatives was a recurring theme. The value of prior discussion about organ donation cannot be overstated, as knowledge about a loved one’s wishes is likely to help facilitate and ease decision-making at a time of great stress, whilst overcoming at least one crucial barrier towards lifting organ donation rates.

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Table 1

Age distribution, partnership status and respondents’ relationship to the deceased (*N* = 50)

Age (years)	**Total (%)**	**Partnership status**	**Total (%)**	**Relationship to deceased**	**Total (%)**
25–34	4.0	Widowed	42.0	Spouse	34.0
35–44	10.0	Married	40.0	Child	18.0
45–54	20.0	Divorced	12.0	Parent	22.0
55–64	32.0	Defacto/partner	2.0	Sibling	18.0
65–74	22.0	Never married	2.0	Other	4.0
75–84	6.0	No response	2.0	No response	4.0
85+	4.0				
No response	2.0				

Table 2

Education level and occupation of respondents (*N* = 50)

Education	**Total (%)**	**Occupation**	**Total (%)**
Postgraduate degree	2.0	Trained professional	36.0
Graduate diploma/certificate	6.0	Clerical/administrative	16.0
Bachelor degree	8.0	Management	8.0
Diploma/advanced diploma	12.0	Community or personal service worker	8.0
Certificate level	36.0	Technician or trades worker	6.0
Secondary education	32.0	Receiving welfare benefits	6.0
Primary education	4.0	Other	16.0
		No response	4.0

Table 3

Country of birth, ethnicity and religion of respondents ($N = 50$)

Country of birth	Total (%)	Ethnicity	Total (%)	Religion	Total (%)
Australia	82.0	Caucasian	96.0	Christianity	62.0
United Kingdom	8.0	No response	4.0	No religion	32.0
Europe (Other)	10.0			No religion but believe in God	4.0
				No response	2.0

Table 4

Feelings about being approached to consider brain donation ($N = 50$)

Categories	Examples	Total (%)
'Positive' comments	Fine, happy, glad, pleased, relieved, good, positive, willing to help, comfortable	30.0
'Neutral' comments	Surprise, okay, unsure, understand, caught off guard, fair	42.0
'Negative' comments	Shocked, numb, apprehensive, sad, uncomfortable, taken aback	36.0

Some individual responses fit more than one category

Table 5

Distress from call offering opportunity to donate relative’s brain (*N* = 50)

	Total (%)
Not upset	74.0
Upset	22.0
‘Yes and no’ response	4.0

Table 6

Respondents' initial thoughts/reaction to request for brain donation ($N = 50$)

	Total (%)
Donation can help others/research	38.0
Deceased would have wanted the donation to occur	16.0
Surprise	16.0
Ok/great idea	12.0
Doubt/apprehension/uncertainty	10.0
Overwhelm	2.0
Relief	2.0
Glad someone was doing something to solve deceased's devastating disease	2.0
'No reaction' to request	2.0

Table 7

Reasons for decision to donate brain tissue ($N = 50$)

	Total (%)
To help others/research	66.0
Deceased’s wishes considered	24.0
No response	6.0
It was the ‘right choice’	2.0
Another family member made the decision (no explanation given)	2.0

Table 8

Prior discussion about organ donation with deceased ($N = 50$)

	Total (%)
Prior discussion	54.0
No prior discussion	44.0
No response	2.0