Why do potential body donors decide against donating?

Kathryn McClea, Mark D Stringer

Abstract

Background The Department of Anatomy at the University of Otago has been accepting body bequests for anatomical study for about 70 years. Donated bodies are used to teach anatomy to medical and dental students and surgical trainees and a wide range of other undergraduate and postgraduate students rely on body specimens to learn anatomy. Maintaining a robust body bequest programme is essential for these educational programmes. The profile of our body donors is reasonably well understood but little is known about why individuals who are interested in body donation decide not to complete the registration process.

Aim To investigate the reason(s) why applicants request bequest information but do not complete the registration process.

Methods In March 2012, an anonymous questionnaire was sent to 142 individuals who had contacted the Department between January 2010 and August 2011 requesting bequest information but had not completed the registration process.

Results Eleven questionnaires failed to reach the intended recipient reducing the sample size to 131. Seventy eight respondents (60%) completed the questionnaire. The prime motivation for enquiring about body donation was a desire to aid medicine. The commonest single reason for not completing the registration process was our donor weight restriction of 90 kg, cited by 25% of respondents. Other reasons included objections by a family member and restrictions related to potential prion disease. Fourteen respondents had lost their registration form, and a further 15 hadn’t yet made up their mind whether to donate; 18 of these have since completed the registration process.

Conclusions Restrictions on the acceptance of a body at the time of death deter some interested individuals from body donation. About 40% of respondents to this survey had either lost their form or were still considering body donation, many of whom were prompted to complete the registration process by this survey. Bequest programmes should consider sending a follow-up letter to individuals who request information but subsequently fail to register within a few months.

The Department of Anatomy at the University of Otago’s Medical School has used cadavers to teach anatomy to health science and science students since 1874. In the early years the Department received unclaimed bodies from mental institutions and poor houses around New Zealand. This tradition continued until 1943 when the first written bequest to the Department was made.¹

The success of the bequest programme is wholly dependent on the generosity and altruism of the people who donate their body to medical science. Previous studies of our donor programme have focused on the background and motivation of our body donors.¹⁻⁴
The Department receives bequest enquiries from about 200 people each year. Approximately 50–60% of these individuals register as body donors but the remainder do not complete the registration process.

The Department completely respects an individual's decision not to donate but we were interested to explore the reasons why those interested in donation fail to complete the registration process. This knowledge could assist us in maintaining a robust bequest programme, which provides such a strong foundation for anatomy education and research. It may also be of interest to General Practitioners with whom patients sometimes discuss body donation.  

Methods

In March 2012 a postal questionnaire was sent to 142 individuals (64% female, 36% male) who had requested information about body donation from the Department between January 2010 and August 2011 but who had not completed the registration process. An information sheet explained that participation was purely voluntary and that responses were anonymous. A freepost reply envelope was included.

The questionnaire comprised a total of 15 questions related to the following: personal information about the respondent (gender, ethnicity, age, marital status); whether they had discussed their plan to donate their body with anyone; the main reason(s) for requesting bequest information; the main reason(s) for deciding not to donate their body; attitudes to current restrictions to donation (Table 1) they would most like to see removed; the possible influence of past moratoria on the acceptance of bodies; the utility of bequest literature sent to them; and whether they would be likely to become a body donor in the future. Finally, participants were invited to add any additional comments.

This study was approved by the University of Otago Ethics Committee (12/020) and the Ngāi Tahu Research Consultation Committee.

Table 1. Current departmental restrictions on the acceptance of a body

<table>
<thead>
<tr>
<th>Restriction</th>
<th>Reason for restriction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body weight &gt;90 kg</td>
<td>Health and safety of staff who handle the bodies</td>
</tr>
<tr>
<td>Infectious diseases: hepatitis B or C, Creutzfeldt-Jakob disease, active tuberculosis, HIV</td>
<td>Embalming does not eliminate risks of these infections</td>
</tr>
<tr>
<td>Recent (&lt;1 month) complicated and/or extensive major surgery</td>
<td>Insufficient healing of wounds</td>
</tr>
<tr>
<td>Rapid or recent (&lt;6 months) onset of dementia</td>
<td>Risks of prion transmission</td>
</tr>
<tr>
<td>Lived in the UK, France or Republic of Ireland for a cumulative period of ≥6 months between 1980 and 1996</td>
<td>Relates to the outbreak of bovine spongiform encephalopathy and the risk of human prion infection</td>
</tr>
<tr>
<td>Post-mortem examination required</td>
<td>Renders the body unsuitable for anatomical study</td>
</tr>
<tr>
<td>Death outside catchment area (Invercargill, Dunedin, Christchurch, Nelson regions)</td>
<td>Logistic reasons of needing to embalm the body within 24 hours of death</td>
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</tbody>
</table>

Results

Response rate—Eleven forms were marked “return to sender” indicating that the recipient no longer lived at the address. Seventy-eight (60%) of the remaining 131 individuals returned a completed questionnaire.
Gender, ethnicity, age and marital status—Fifty-two respondents (67%) were female, a similar proportion to the overall survey cohort. The majority of all respondents (n=74 [95%]) identified themselves as being of New Zealand European descent, with the remaining four respondents being of Māori, New Zealand Moriori, European, and American descent, respectively.

Most respondents were aged in their 60s (n=21 [27%]) or 70s (n=23 [29%]); seven (9%) were in their 80s and the remainder (35%) were younger (two in their 20s, 11 in their 40s, and 14 in their 50s). Forty-two respondents (54%) were married or in a long-term relationship, 18 (23%) were divorced or separated, 10 (13%) were widowed, and the remainder were single. Sixty-one respondents (78%) had discussed their wishes with at least one other person prior to requesting information.

Main reason(s) for requesting bequest information—A total of 102 main reasons were given by the 78 respondents, 17 respondents giving two or more reasons. The main motivation for more than half of all respondents (n=46 [59%]) was a desire to give something back to the medical profession (Figure 1). Another 28 (36%) respondents echoed this altruistic theme by indicating they had always wanted to donate their body to medical science.

Some respondents added comments about specific health problems that they and/or their family members had experienced and their desire to assist with the training and education of future health care professionals. One respondent indicated that she had a rare condition that she thought would be interesting for the students.

Only thirteen (17%) respondents indicated that their main reason for requesting information was because they did not want their estate to pay funeral expenses, or that they did not like funerals. One respondent made the following comment: “I have been to a funeral where the body went to Dunedin [Otago School of Medical Sciences] and this was one of the best funerals I have been to.”

Other reasons for wanting bequest information included the 2009 and 2010 airing of the documentary *Donated to Science* on TV3, and a general desire to know more about body donation.

Figure 1. Main reason(s) for requesting bequest information
Main reason(s) for deciding not to donate—A total of 83 responses were given by 70 respondents, with 12 people giving more than one reason. Eight people declined to answer this question.

Seventeen (24%) respondents indicated that their current body weight was the main reason for not proceeding (Figure 2). Fourteen (20%) respondents stated that they had lost or misplaced the registration form, eight of whom requested a further form.

Fifteen (21%) respondents indicated they were still considering body donation but had not yet reached a decision. Six respondents were unable to register because they had lived in the UK, France or Republic of Ireland for a cumulative period of 6 months or more between 1980 and 1996.

Nine respondents indicated they had rejected donation because of objections by family members. Five respondents stated that the uncertainty of not knowing until the time of death whether their body would be accepted was the reason they had not proceeded.

Four “other” responses were given: one respondent wanted his body to be used specifically for research into polio and chronic fatigue syndrome which is not within the Department's remit; another wished to donate but was allowing his family more time to accept his decision; one respondent considered that he would be ineligible for donation after an anticipated knee replacement; and another stated that her Bahai faith did not allow the body to be cremated (which is carried out after dissection).

Figure 2. Main reason(s) for not proceeding with body donation
Attitudes to restrictions—Forty-five respondents (58%) stated they would think more positively about donating if there were not so many restrictions on the acceptance of bodies. Sixty-two listed the restriction(s) they would most like to see removed (Figure 3); in 23 instances this was the body weight limit.

Figure 3. Restrictions on body donation respondents would most like to see removed

<table>
<thead>
<tr>
<th>Restriction</th>
<th>No. of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body weight</td>
<td>25</td>
</tr>
<tr>
<td>Lived in UK/France/Ireland</td>
<td>15</td>
</tr>
<tr>
<td>Rapid onset of dementia</td>
<td>10</td>
</tr>
<tr>
<td>Passed away outside area</td>
<td>10</td>
</tr>
<tr>
<td>Recent major surgery before death</td>
<td>5</td>
</tr>
<tr>
<td>Infectious diseases</td>
<td>5</td>
</tr>
</tbody>
</table>

*Based on 66 responses given by 62 respondents

Past moratoria—The Department previously placed a moratorium on the acceptance of bodies on two separate occasions when it reached its capacity to store bodies. In 1993, the moratorium lasted for a period of 18 months, whereas in 2008 it was for 6 months only. Registration of bequests continued to be accepted during both periods. Half of the respondents (n=38 [49%]) were unaware of these events, 27 (35%) did not answer this question, and only two of the 13 respondents who had been aware of past moratoria indicated that it had influenced their decision not to donate.

Utility of bequest information literature—Seventy-three (94%) respondents indicated that the bequest information pamphlet they received from the Department was helpful in making a decision about donating their body; the other five did not answer this question. Four respondents commented on additional information they would like to see included: two wanted to know exactly how their body would be used, another asked for an easy step-by-step instruction guide on how to donate, and the fourth stated they had previously contacted the Department to ask if suicide would affect their bequest.

Likelihood of future body donation—Of the 64 respondents who answered this question, 41 stated that they may yet decide to donate their body. 12 ruled this out, and 11 were uncertain. Eleven commented that they would reconsider donating if they could reduce their body weight to within the Department’s limit.
Five respondents commented on the restriction imposed by living overseas e.g. “I would be very happy to sign-up if there was some way around the residency in the UK condition” and one questioned why the Department would not be able to accept their body if they committed suicide.

Discussion

To our knowledge, this is the first study to explore the reasons why individuals expressing an interest in body donation do not complete the registration process. The 60% response rate to our questionnaire was gratifying given that the participants had not replied previously to bequest information sent to them.

The Department endeavours to accept all body bequests, but there are inevitable restrictions centred around the safety of staff and students and the logistics of body donation, and it appears that these are a significant factor for some individuals considering body donation.

Reasons for not completing the bequest registration process:

- This survey showed that the commonest single reason for not proceeding with donation was a body weight greater than 90kg; this was cited by a quarter of those who answered this question. All bequest programmes in Australia and New Zealand have a donor weight restriction because of health and safety concerns for staff who are required to lift and turn the bodies. As the mean body weight of New Zealand adults increases this restriction will have a progressively greater impact on our bequest programme.

- It was interesting to note that 29 (42%) respondents had not actually decided against donating their body and were either still considering donation or had lost their registration form. Eighteen of these respondents have since completed the bequest registration process, suggesting that bequest programmes would benefit from contacting non-respondents with a single follow-up letter.

- Encouragingly, past moratoria do not appear to have had a major impact on this group of potential donor’s perceptions of the bequest programme. Only two respondents stated that this had played a part in their decision not to donate. Nevertheless, bequest programmes should ideally have the necessary infrastructure to accommodate fluctuations in the number of body donations, without the need for potentially disruptive temporary moratoria.

- One in eight potential donors in this survey did not complete the registration process because of objections by a family member. Despite there being a next-of-kin’s co-signature on the registration form, the Department is unable to accept a body at the time of death if a near living relative objects to the bequest. Several respondents indicated that they were still hoping that family members would change their minds and support their wish to donate. One respondent went so far as to state that they would like to see legislation preventing relatives from overriding the wishes of the donor. This is also a controversial issue in organ donation. The law governing body donation to New Zealand schools of anatomy was revised in 2008 (Human Tissue Act 2008) so it is unlikely that any such changes will be made in the near future.
The donor restriction related to living in the United Kingdom, France or Republic of Ireland for 6 months or more between 1980 and 1996 relates to the European outbreak of bovine spongiform encephalopathy (BSE or "mad cow disease") during that period and the possibility of human prion infection. Prions are not eliminated by conventional embalming agents. This criterion is the same as that used by the New Zealand Blood Service and other bequest programmes in Australasia but the evidence is largely circumstantial. These same individuals are eligible to donate organs and corneas for transplantation but not heart valves, skin or other tissue.

The issue of suicide and body donation was raised by two respondents. A coroner's post-mortem in such cases renders the body unsuitable for anatomical examination. This is common to bequest programmes throughout Australasia. An increasing awareness of physician-assisted suicide and its possible greater acceptance in society in the future could therefore become an issue for bequest programmes.

As in previous retrospective and prospective studies of registered body bequestees at our medical school and similar studies in other countries, the overwhelming motivation to donate was a desire to aid medicine. A common misconception about bequest programmes is that the avoidance of funeral expenses is an important driver. Only five (6%) respondents in this study indicated that their main reason for requesting bequest information was to avoid funeral expenses. This is an identical proportion to that found in our retrospective study of 140 registered body bequestees.

While the pros and cons of maintaining a body bequest programme continue to be debated, there is some evidence that access to human specimens is a crucial factor in maintaining high standards in anatomical education and research.

Respecting and understanding our body donors should be part of this privilege. This study offers new insights into our potential donor population and suggests that bequest programmes might benefit from following up individuals who express an interest in body donation but fail to complete the registration process.

Competing interests: Nil.

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