

Modifiable factors influencing relatives' decision to offer organ donation: systematic review

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ABSTRACT

Objective To identify modifiable factors that influence relatives' decision to allow organ donation.

Design Systematic review.

Data sources Medline, Embase, and CINAHL, without language restriction, searched to April 2008.

Review methods Three authors independently assessed the eligibility of the identified studies. We excluded studies that examined only factors affecting consent that could not be altered, such as donor ethnicity. We extracted quantitative results to an electronic database. For data synthesis, we summarised the results of studies comparing similar themes.

Results We included 20 observational studies and audits. There were no randomised controlled trials. The main factors associated with reduced rates of refusal were the provision of adequate information on the process of organ donation and its benefits; high quality of care of potential organ donors; ensuring relatives had a clear understanding of brain stem death; separating the request for organ donation from notification that the patient had died; making the request in a private setting; and using trained and experienced individuals to make the request.

Conclusions Limited evidence suggests that there are modifiable factors in the process of requests for organ donation, in particular the skills of the individual making the request and the timing of this conversation, that might have a significant impact on rates of consent. Targeting these factors might have a greater and more immediate effect on the number of organs for donation than legislative or other long term strategies.

INTRODUCTION

Solid organ transplantation is an integral part of modern health care. It is, however, a victim of its own success as demand for organs now far exceeds supply. In the past decade the number of patients waiting for solid organs has increased by 70%,^{w1} while the number of organ donors has not significantly increased. Every day in the United Kingdom about one patient on a transplant waiting list dies.¹

The greatest identified impediment to organ donation from patients after brain stem death on an intensive care unit in the UK is refusal of consent by the

relatives of the donor.^{2-4w2} A recent audit of all deaths in 341 intensive care units in the UK over a 33 month period showed that 41% of the relatives of potential organ donors refused to consent to donation.¹

Although the Human Tissue Act 2004,⁵ which came into force in 2006, prioritises the wishes and consent of the potential donor over the relatives, it is almost inconceivable that organs would be retrieved from a brain stem dead patient against the wishes of his or her family. Thus requests to relatives for organ donation are likely to remain an important step in organ procurement.

Interviews with the relatives of brain stem dead patients have shown that about a third of those who refused donation would not make the same decision again,^{w3} whereas few consenting relatives regretted their decision, suggesting that many decisions to refuse to allow donation are not based on deeply held religious or other views, and that there might be factors in the way the request for donation is made that could change the decision. Identifying these factors, and making this information available to intensive care clinicians and transplant professionals, might have a greater and more immediate effect than any legislation. We reviewed published peer reviewed studies to identify any modifiable factors in the request for organ donation that might increase consent rates.

METHODS

Searching—On 8 May 2008 we searched Medline (from 1950), Embase (from 1980), and CINAHL (from 1982) using the OVID database search programme (<http://ovidsp.tx.ovid.com/spb/ovidweb.cgi>). We used the search terms “organ” or “tissue” and “don*” or “consent” in the title or abstract and limited the search to humans without language restrictions. These terms were finalised after trial searches undertaken to maximise the number of citations found and to ensure that we detected all relevant citations known to us before searching. We deliberately kept the search terms broad to avoid losing potentially important papers. We hand searched reference lists of included studies to identify other potentially relevant studies.

Inclusion and exclusion criteria—We included studies that reported factors associated with the consent

outcome of a request for organ donation to the relatives of a beating heart potential organ donor (a patient meeting the criteria for brain stem death). We included studies looking at both child and adult organ donors, regardless of the original publication language. We included all studies containing data, whether from observational or interventional studies. We excluded studies if they examined factors affecting consent that we deemed unmodifiable (for example, religious, cultural, geographical, and ethnic influences) or if they looked at other reasons for the disparity between potential and actual donors (for example, incomplete neurological assessment of patients and medical unsuitability of some consented donors). We also excluded narrative pieces without data to support observations.

Validity assessment and data abstraction—Three authors (ALS, LCR, VSB) screened the obtained titles and abstracts for eligibility. We excluded papers first on title, then abstract, and finally on full text. When studies seemed to meet eligibility criteria (or when information was insufficient to exclude them), we obtained the full text articles. We extracted any quantitative results to an electronic database.

Data synthesis—As the identified papers did not contain data suitable for meta-analysis, we reviewed them to identify all the modifiable factors associated with agreement or refusal of consent. Common themes emerged so we report the results in narrative form under thematic headings.

RESULTS

Trial flow

Database searching produced a list of 22 032 publications. Of these, we excluded 21 147 using information in the title alone and 639 using information in the abstract. We reviewed 246 full papers (figure). No further papers were identified from the reference lists of these papers. After we excluded 226 papers that did not meet the inclusion criteria, we included 20 studies in the review.^{w1-w20}

Study characteristics

The studies identified were of two types. In observational studies the proportion of successful requests for organ donation was determined when the factor was present and compared with the proportion when it was not. In “before and after” audits the factor was modified and the effect on subsequent organ donation noted. We did not identify any randomised controlled trials. One study included data from a previous publication.^{w12 w13} Two studies reported data collected from the same hospitals over the same period with near identical record numbers, though no mention was made of duplicate publication.^{w1 w20}

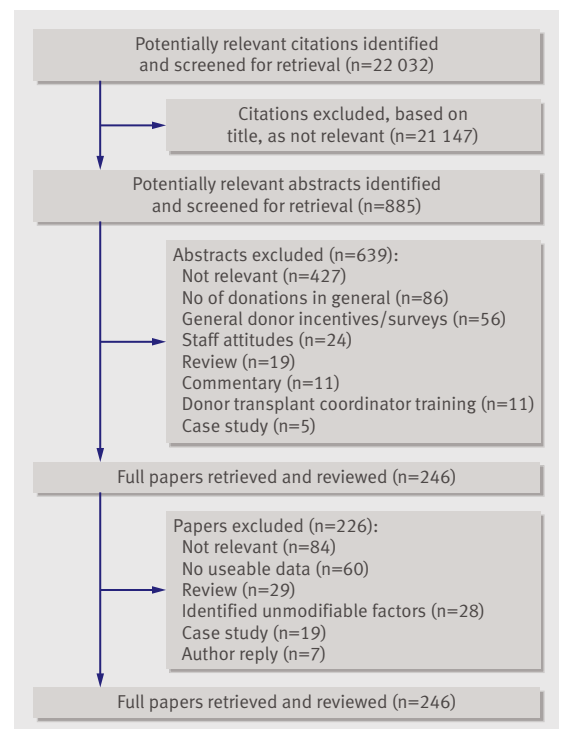
Data synthesis

We identified modifiable factors that apparently influence relatives’ decisions to allow organ donation in six broad categories: information discussed during the request; perceived quality of care of the donor;

understanding of brain stem death; specific timing of the request; setting in which the request is made; and approach and expertise of the individual making the request. Many of the papers report multiple factors and thus appear under several headings. We present all the modifiable factors identified in studies with a P value of ≤ 0.05 for differences in the observed proportion of relatives giving consent to organ donation with the factor present or absent. We also present modifiable factors for which no statistical results were reported but which the authors considered relevant.

Information discussed during request

Five studies retrospectively collected data via chart reviews and interviews with staff and families in an attempt to establish whether information provided during the request process was associated with the family’s decision to donate or not donate organs for transplantation (table 1).^{w1 w3 w5 w18 w20} Siminoff et al studied 420 donor eligible patients.^{w1 w20} Factors correlating with consent to organ donation were delivery of information on the costs of donation; the impact of donation on funeral arrangements; and assurances that the family had a choice about which organs to donate. When healthcare professionals mentioned that donation had the potential to help others, families were also more likely to donate, but telling families that they were required to ask about donation had a negative impact on consent rates.^{w1} The other papers showed a significantly higher rate of consent when families thought they had been given enough information to make an informed decision about organ donation,^{w3 w5 w18 w20} in particular understanding that a



Review flow chart

Table 1 | Studies showing association between information discussed during request for organ donation and consent rate for organ donation. Numbers are percentages of relatives consenting to organ donation when factor was present or not, unless stated otherwise

Study	No studied	Type of study	Factors associated with consent	% consenting		P value
				With factor	Without factor	
Siminoff et al, ^{w1} 2001, US	420	Retrospective data collection via chart reviews, and telephone interviews with healthcare practitioners or organ procurement organisation (OPO) staff, and face to face interviews with family for all donor eligible deaths	Cost of donation; impact of donation on funeral arrangements; assurances that family had choice about which organs to donate	NA	NA	<0.002 (across groups)
			Mean No of discussions regarding organ donation	2.4	2	
			Told family that they were required to ask about donation	44	62*	
			Told family of potential to help others	72	39*	
DeJong et al, ^{w3} 1998, US	164	Structured telephone interview with immediate next of kin 4-6 months after death of relative	Family thought that they were given enough information to make informed decision about organ donation	95	67	<0.01
			Family aware of needs based organ allocation	44	24	<0.02
			Family aware of benefits of donation	93	68	<0.01
			Family aware donation is cost neutral	83	50	<0.01
			Family understood that regular funeral service was possible after organ donation	92	73	<0.001
Rosel et al, ^{w5} 1999, Spain	71	Postal survey sent to all families who had been approached for organ donation at single hospital within 12 month period	Family aware of needs based organ allocation	NA	NA	<0.01
Rodrigue et al, ^{w4} 2003, US	1014	Structured telephone interview with next of kin	Families thought enough information given	89	56	<0.001
			Families thought information presented clearly	89	73	<0.001
Siminoff et al, ^{w20} 2002, US	420	Retrospective data collection via chart reviews, telephone, and face to face interviews	Families thought enough information discussed	65	41	0.001

NA=not available (data not given); OPO=organ procurement organisation.

*Calculated from published data.

regular funeral service is still possible after organ donation.^{w3}

Perceived quality of care of donor

Perceived quality of care during the hospital stay had a significant impact on consent rates in the three papers that examined this (table 2).^{w1 w3 w4} All three papers showed that a negative perception of care results in a decreased rate of consent.

Understanding of brain stem death

In five papers there was a significant association between understanding and consent to organ donation,^{w1 w3-w6} with a sixth paper showing a non-significant increase in consent in families who understand brain stem death but a significant difference in consent rates in families accepting the concept of brain stem death (table 3).^{w19} In 71 families surveyed, 48 (68%) who did consent had a significantly better understanding of the concept of brain stem death than 23 (32%) who did not consent.^{w5} Similarly, in a review of 285 families, 71% that had complete knowledge of brain stem death agreed to donation compared with only 29% of those with incomplete or inaccurate knowledge of brain stem death.^{w4} When families were asked if they agreed that people cannot recover when they are brain dead, 80% of donor family respondents correctly agreed with this statement, while only 48% of the

non-donor family group did so.^{w3} In a study by Jenkins et al a protocol that used a nuclear medicine brain flow scan to confirm brain stem death increased consent from 44% to 71%, perhaps because of its objective nature.^{w6}

Timing of the request

A series of nine reports all suggested that there is an improved rate of consent when there is temporal separation (“decoupling”) between notification and acceptance of brain stem death and request for donation (table 4).^{w1 w2 w3 w4 w7-w9 w14 w18}

The most important factor seems to be that the request for donation does not occur at the same time as the notification of death or testing for brain stem death. Niles and Mattice studied the timing in the approach process and determined that the consent rate was similar regardless of whether families were approached either before (62%) or after (57%) death but much lower when donation was mentioned at the time of the death notification (25%).^{w9} Siminoff et al showed a slightly different result, suggesting that requests coinciding with testing for brain stem death reduced consent rates.^{w1} In a retrospective study in which 285 next of kin were interviewed, 68% consented to donation if they thought the timing of the discussion about donation was appropriate whereas only 18% consented if they considered the timing to

Table 2 | Studies showing association between perceived quality of care of potential organ donor and consent rate for organ donation. Numbers are percentages of relatives consenting to organ donation when factor was present or not

Study	No studied	Type of study	Factors associated with consent	% consenting		P value
				With factor	Without factor	
Siminoff et al, ^{w1} 2001, USA	420	Retrospective data collection via chart reviews and telephone interviews with healthcare practitioners or OPO staff, and face to face interviews with family for all donor eligible deaths	Families believed that one or more healthcare professional involved in relatives' care was not caring or concerned	43	59*	0.04
DeJong et al, ^{w3} 1998, US	164	Structured telephone interview with immediate next of kin 4-6 months after death of relative	Perceptions of overall quality of care delivered in hospital (scale devised; score >5)	82	48	<0.01
			Thought relative had received best possible care before death	92	70	<0.001
Rodrigue et al, ^{w4} 2006, US	285	Retrospective structured telephone interview with next of kin of donor eligible dead individuals	Overall satisfaction with care received higher for next of kin who consented to donation	45	39	<0.001

OPO=organ procurement organisation.
*Calculated from published data.

be poor.^{w4} Overall, there was no clear consensus on the optimum timing of a request other than avoiding linking the request with notification of death or the tests for brain stem death.

Giving families enough time to make a decision was also important.^{w1 w3 w4 w18} Many families (60%) who thought that they had ample time for discussion consented to donation, while only 27% of those who thought they had insufficient time for discussion did so.^{w4} Two studies found that families who felt harassed or pressured to make a decision were less likely to donate.^{w1 w18} In another study that retrospectively interviewed the immediate next of kin of 164 medically suitable potential organ donors, 83% of donor and 56% of non-donor family respondents said that they were given enough time to understand that their relative was dead before medical staff brought up organ donation.^{w3}

Setting in which the request is made

Evidence that a private location for discussion about organ donation improves consent rates is clearly documented.^{w2 w3} In two studies consent rates for requests made in settings that provided little privacy (requests made by telephone, in the patient's room, at the nursing station, or in the hallway) were 45% and 30% compared with consent rates of 56% and 52% in more private settings (table 5).^{w2 w3} One study showed no significant benefit of a private setting for organ donation requests.^{w20}

Approach and expertise of the person making the request

The most studied factor influencing consent is the approach and expertise of the person making the request. Fourteen studies investigated this (tables 6 and 7).^{w1 w2 w3 w4 w5 w7 w10-w17} Differences in consent

Table 3 | Studies showing association between relatives' understanding of brain stem death and consent rate for organ donation. Numbers are percentages of relatives consenting to organ donation when factor was present or not

Study	No studied	Type of study	Factors associated with consent	% consenting		P value
				With factor	Without factor	
Siminoff et al, ^{w1} 2001, US	420	Retrospective data collection via chart reviews, and telephone interviews with healthcare practitioners or OPO staff, and face to face interviews with family for all donor eligible deaths	Family believed patient had died when brain stem death was confirmed	63	48*	0.001
DeJong et al, ^{w3} 1998, US	164	Structured telephone interview with immediate next of kin 4-6 months after death of relative	Family understood that people cannot recover when they are brain stem dead	80	48	<0.001
			Family understood someone is brain stem dead even though heart is still beating	80	60	<0.02
Rodrigue et al, ^{w4} 2006, US	285	Retrospective structured telephone interview with next of kin of donor eligible deceased individuals	Adequate knowledge of brain stem death	71	27*	<0.001
			Explanation of brain stem death given	74	43*	<0.001
Rosel et al, ^{w5} 1999, Spain	71	Postal survey sent to all families who had been approached for organ donation at single hospital within 12 month period	Understanding of brain stem death	NA	NA	<0.01
Jenkins et al, ^{w6} 1998, US	NA	Before and after study after implementation of rapid brain death protocol	After rapid brain stem death protocol with nuclear medicine scan to confirm brain death consent rate increased	71	44	<0.01
Frutos et al, ^{w19} 1998-2003, Spain	268	Family interview with families of possible donors accepted for transplant	Acceptance of brain stem death	67	51	0.044

OPO=organ procurement organisation; NA=not available (data not given).
*Calculated from published data.

Table 4 | Studies showing association between timing of request for organ donation and consent rate for organ donation. Numbers are percentages of relatives consenting to organ donation when factor present or not

Study	No studied	Type of study	Factors associated with consent	% consenting		P value
				With factor	Without factor	
Siminoff et al, ^{w1} 2001, US	420	Retrospective data collection via chart reviews, and telephone interviews with healthcare practitioners or OPO staff, and face to face interviews with family for all donor eligible deaths	Organ donation mentioned while brain death tests conducted	65	56*	0.04
DeJong et al, ^{w3} 1998, US	164	Structured telephone interview with immediate next of kin 4-6 months after death of relative	Subject of organ donation brought up after family given enough time to understand that relative was brain stem dead	83	56	<0.001
Rodrigue et al, ^{w4} 2006, US	285	Retrospective structured telephone interview with next of kin of donor eligible deceased individuals	Relatives thought timing of request appropriate	68	18*	<0.001
			Relatives thought they were given enough time to discuss donation	60	27*	<0.001
Niles et al, ^{w9} 1996, US	127	Retrospective study with data collection questionnaire	Organ donation requested before death	62	—	—
			Organ donation requested after death	57	—	0.07*
			Organ donation requested at same time as family told of patient's death	25	—	—
Gortmaker et al, ^{w2} 1998, US	707	Data collected prospectively for medically suitable potential donors referred to three organ procurement organisations	Request decoupled (not at same time as death notification)	72	53	<0.001
von Pohle et al, ^{w7} 1996, US	68	Retrospective chart review	Request decoupled (not at same time as death notification)	86	25	<0.05
Garrison et al, ^{w8} 1991, US	155	Retrospective review	Request decoupled (not at same time as death notification)	65	18	<0.05
Evanisko et al, ^{w14} 1998, US	1061	Staff questionnaire	More respondents from hospitals with high donation rates (40.6%) than respondents from hospitals with low donation rates (30.0%) knew that appropriate time to bring up topic of organ donation was after brain death had been determined (decoupled); P=0.04	—	—	—
Rodrigue et al, ^{w18} 2003, US	1014	Structured telephone interview with next of kin	Relatives felt pressured to donate	2	6	<0.001
			Relatives had enough time to decide	86	58	<0.001

OPO=organ procurement organisation.
*Calculated from published data.

rates seem to be associated with which professionals are involved with the request process.^{w1 w2 w4 w7 w10 w11}

In a study of 707 requests for organ donation, a combined approach by hospital staff and coordinators from an organ procurement organisation (OPO) resulted in a consent rate of 72%. Hospital staff alone had a consent rate 53%, while coordinators alone had a consent rate 62%.^{w2} Similarly, a retrospective study in Texas of 185 medically suitable organ donors over one year showed that the consent rate was 67% when the OPO coordinator approached the family alone, 9% when hospital staff approached the family alone, and 75% when the approach was made jointly.^{w10}

Families have reported that conversations with OPO staff were crucial to their donation decision. Talking to a member of OPO staff before being asked to make a decision and spending more time with a member of OPO staff were both strongly associated with donation.^{w1}

Shafer et al conducted a four year retrospective study in a large 500 bed public trauma hospital.^{w12} An independent organ procurement organisation hired two in house coordinators, one white and one black, to work exclusively in the hospital, closely managing and coordinating the consent process. After implementation of the programme and the use of race specific

Table 5 | Studies showing association between setting in which request for organ donation was made and consent rate for organ donation. Numbers are percentages of relatives consenting to organ donation when factor was present or not

Author	No studied	Type of study	Factors associated with consent	% consenting		P value
				With factor	Without factor	
Gortmaker et al, ^{w2} 1998, US	707	Data collected prospectively for medically suitable potential donors referred to three OPOs	Place of request private	67	45	<0.001
DeJong et al, ^{w3} 1998, US	164	Structured telephone interview with immediate next of kin 4-6 months after death of relative	Setting provided little privacy (hallway/ waiting room)	30	52	<0.02

OPO=organ procurement organisation.

requestors, there was a 64% increase in the consent rate and an overall increase of 94% in the number of organ donors. There were significant increases in consent across all racial and ethnic groups, with the largest increases noted in minority populations. A comparison of level 1 trauma centres in the US with and without in house coordinators showed that conversion of potential organ donors to actual donors was 48% greater in centres with in house coordinators.^{w13} Similarly, a retrospective analysis of 495 patients referred to the regional organ procurement organisation for possible organ donation recorded a rise in the consent rate from 35% to 52% with the implementation of an in house coordinator.^{w17}

There is a correlation between staff training in effective procedures for requesting organ donation and donation rates.^{w14-w16} In hospitals with high rates of organ donation, 53% of the staff had received training compared with 24% of staff in hospitals with low rates of organ donation.^{w14} Interestingly, the consent rate seems to differ with time of year, relating to medical

skill. In the US new medical residents enter their respective programmes in July. One study found that the consent rate for May to June was 67% compared with 31% for July to December of the same year.^{w15} Finally, it seems that courtesy increases organ donation rates.^{w5}

DISCUSSION

The main modifiable factors significantly associated with whether relatives deny or allow organ donation were information discussed during the request, perceived quality of care of the donor, understanding of brain stem death, specific timing of the request, setting in which the request is made, and the approach and skill of the individual making the request. Ensuring that adequate time is available both to make the request and to allow families to consider the request also seems important. Many of these findings are unsurprising. For example, it is standard practice when “breaking bad news” to families and individuals in a medical setting to pace the sequence of information provided and

Table 6 | Studies showing association between approach and expertise of person making request for organ donation and consent rate for organ donation. Numbers are percentages of relatives consenting to organ donation when factor was present or not, unless stated otherwise

Author	No studied	Type of study	Factors associated with consent to organ donation	% consenting		P value
				With factor	Without factor	
Siminoff et al, ^{w1} 2001, US	420	Retrospective data collection via chart reviews, telephone interviews with healthcare practitioners or OPO staff, and face to face interviews with family for all donor eligible deaths	Mean comfort of healthcare professionals with answering families' questions about donation (0-10 scale)	9.3	9	<0.001
			Relatives felt harassed or pressurised to make decision	34	59*	0.002
			Healthcare professional other than physician broached possibility of organ donation, followed by meeting with OPO staff person	NA	NA	<0.001
			Mean time spent with OPO (mins)	3.6	1	<0.001
Gortmaker et al, ^{w2} 1998, US	707	Data collected prospectively for medically suitable potential donors who had been referred to three organ procurement organisations	Hospital staff and OPO coordinators involved in request	72	—	<0.001 (across groups)
			Request by OPO staff alone	62	—	
			Request by hospital staff alone	53	—	
DeJong et al, ^{w3} 1998, US	164	Structured telephone interview with immediate next of kin 4-6 months after death of relative	Hospital staff first mentioned donation	52	29	0.03 (across groups)
			OPO coordinator first mentioned donation	13	16	
			Person formally asking for donation first mentioned donation	NA	NA	
Rodrigue et al, ^{w4} 2006, US	285	Retrospective structured telephone interview with next of kin of donor eligible dead individuals	OPO staff first mentioned request	72	34	<0.001
			Perceived requestor very compassionate	67	25*	<0.001
Rosel et al, ^{w5} 1999, Spain	71	Postal survey sent to all families who had been approached for organ donation at single hospital within 12 month period	Manners of requesting doctor	NA	NA	<0.01
von Pohle et al, ^{w7} 1996, US	81	Retrospective chart review	Request by OPO staff	89	—	<0.05 (across groups)
			Request by physician	4	—	
Klieger et al, ^{w10} 1994, US	185	Retrospective review	Request by OPO staff alone	67	—	<0.001 (across groups)
			Request by hospital staff alone	9	—	
			Hospital staff and OPO involved in request	75	—	
Evanisko et al, ^{w14} 1998, US	1061	Staff questionnaire	Staff training (how to request organ donation, explaining brain death, counselling grieving family). In hospitals with high rates of organ donation, 52.9% of staff had received training; in hospitals with low rates of organ donation, 23.5% of staff had received training	Before change	After change	<0.01

OPO=organ procurement organisation; NA=not available, data not given; non-significant difference, actual P value not reported..

*Calculated from published data.

Table 7 | Before and after audit studies of practice change showing association between approach and expertise of person making request for organ donation and consent rate for organ donation. Numbers are percentages of relatives consenting to organ donation when factor was present or not

Author	No studied	Type of study	Factors associated with consent to organ donation	% consenting		P value
				With factor	Without factor	
von Pohle et al, ^{w7} 1996, US	61 before, 35 after	Retrospective chart review	Rate of donation increased with addition of institutionally dedicated organ procurement organisation representative and routine use of decoupling	38	59	<0.05
Helms et al, ^{w11} 2004, US	164 before, 137 after	Prospective collection of data compared with data before installation of neurointensivist led team	Consent rate increased after policy change in unit (uncoupling and removal of treating physician from donation requests; request made by procurement officer)	23	37	0.01
			Consent rates for donations in NCCU after policy change, were significantly higher than in other intensive care units in same hospital (36.5% v 22.4%, P=0.003)	37	22	0.003
Shafer et al, ^{w12} 1998, US	313 before, 112 after	Retrospective study before and after implementation of in-house coordinator in hospital with level 1 trauma centre	Implementation of in-house coordinators: consent rate increased	45	74	<0.001*
Shafer et al, ^{w13} 2003, US	770 before, 2284 after Includes data from ref ^{w12}	Retrospective evaluation of in-house coordinator programme in 2 hospitals with trauma centres	Placement of in-house coordinators within trauma centres: consent rate averaged 67%, representing 37% increase above period before in-house coordinators	49	67	<0.001*
			Trauma centres with in-house coordinators had 28% greater consent rate and 48% greater conversion rate of potential donors to actual donors than other 85 level 1 trauma centres	NA	NA	NA
Riker et al, ^{w16} 1995, US	155 before, 49 after	Non-randomised, controlled, before and after intervention trial	Evaluated consent rate after two 1 hour educational sessions with emergency physicians v control group of consulting physicians. After intervention emergency physician consent rate increased from 0% to 32% (P<0.001) but control group consent rate increased from 2.6% to 6.6%	0	32	NC
Linyear et al, ^{w15} 1999, US	42 before, 47 after	Retrospective medical record review; observational study after implementation of family support and communication protocol	Protocol: private setting; decoupling; request by OPO with family communication coordinator/hospital staff	49	72	NA
			Consent rate 67% for May and June v 31% for July to December (new residents)	67 (experienced residents)	31 (new residents)	NA
Salim et al, ^{w17} 2007, US	287 before, 208 after	Retrospective analysis of patients referred to regional OPO for possible organ donation comparing family consent rates before and after implementation of in-house coordinator programme	In house coordinator associated with higher consent rate	35	52	<0.01

NCCU=neurosciences critical care unit; NA=not available, data not given; NC=not calculable; OPO=organ procurement organisation.

*Calculated from published data.

deliver the news in a private and quiet location.⁶ The idea of decoupling pronouncement of death and requests for organ donation is at least 20 years old. A study conducted by Kentucky Organ Donor Affiliates in 1989-90 reported that consent rates increased from 18% to 60% if there was a separation of time between the pronouncement of death and the approach for organ donation.^{w8}

Limitations and strengths

Our review will identify only those factors that have been studied and reported and only those at the level of individual requests. Factors modifiable at a population level, such as the fraction of the population participating in an organ donor register, and some factors modifiable at a hospital level, such as local donation champions, did not appear in the identified studies. Many of the studies identified were retrospective

reviews of medical records. There was a large reliance on hospital or OPO staff as data collectors, who might not be unbiased observers. Most of the studies were based on small numbers, and there were no randomised controlled studies from which to draw data. Several of the studies were based on structured interviews with donor and non-donor families, with little detail on whether the sample interviewed are representative of the whole. These interviews were based on family recollections and thus are accurate only to the extent that their memories of these events are accurate, introducing recall bias. Finally, as the studies are observational, factors correlated with consent to organ donation might not be causative.

The current literature comes almost exclusively from the US. The donation rates seen in many of these studies are higher than those in the UK⁷ so there is some reason to believe that similar strategies

WHAT IS ALREADY KNOWN ON THIS TOPIC

There is a severe shortage of organs for transplantation
The largest impediment to organ procurement is relatives' refusal

WHAT THIS STUDY ADDS

The timing of the request and the person making the request have a significant impact on consent rates
Modifying the consent request process might be the fastest way to increase organ donation rates
These changes could be implemented without undue delay in the UK

might have an even larger effect in the UK, where similar organ procurement structures exist.

The two factors that had the largest effect on consent rates were the person making the request and the timing of this conversation. These studies show that the requestor might have a significantly positive or negative effect on the outcome of the request process. Consent rates were higher when the request was made by the organ procurement coordinator (donor transplant coordinator in the UK) in conjunction with hospital staff members. This is often termed “collaborative requesting.” Clearly, it is not possible to place a dedicated donor transplant coordinator in every hospital that has the potential to produce organ donors because their donor pool might be quite small and this would not be cost effective. It might be possible, however, to consider this in hospitals with larger numbers of potential organ donors, such as regional neuroscience centres. UK Transplant, which provides support to transplant services in the UK, has adopted this strategy.

There is a need for large rigorously conducted intervention studies to test the factors that might be modified to increase organ donation. One such study examining methods to increase donation rates in the UK is under way: the randomised controlled ACRE

(assessment of collaborative requesting) study looking at the effect of “collaborative requesting” on organ donation rates in the UK (ISRCT1169903) is the first such study in the world. It is hoped that findings from this might help in the future to increase donation rates and ultimately save lives.

The assumption underlying the ACRE study, and all the studies reported in this review, is that organ donation is of sufficient benefit to society generally, and to organ recipients specifically, to justify the study and modification of organ donation requests to maximise consent. The point at which fine tuning request procedures might be considered coercion requires further discussion and clarification.

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