

Assessing potential non-directed altruistic kidney donors: a case note audit

Kidney transplantation is now generally accepted as the preferred mode of renal replacement therapy,¹ as it has superior long-term survival compared with dialysis treatment.²⁻⁴ However, kidney transplantation is limited by the shortage of donor organs; currently, approximately 7,500 patients are on the transplant list for a kidney donation in the UK.⁵

Due to the shortage of deceased donor organs and the advantages of living donor transplants, living donors have become an increasingly valuable resource.¹ Advances in immunosuppression have led to better graft survival – even in human leucocyte antigen mismatch^{6,7} – as well as low morbidity associated with the donor operation and an optimistic medical outlook in those with a single kidney.^{8,9} This, in turn, has led to an increase in the number of living donors.

In 2004, the Human Tissue Act was introduced in the UK; this allowed non-directed altruistic (rather than blood-related or emotionally related) organ donation.¹⁰

Altruistic donation

The act of donating a kidney or any other organ to a stranger without any direct reimbursement may be difficult for many to understand, and the question emerges as to whether non-directed altruistic donors (NDADs) have a specific type of psychological profile, background or cultural/religious beliefs that warrants further exploration. However, few up-to-date, systematic data on this topic are available in the UK, particularly because non-directed organ donation is a relatively recent development.

A study published in the USA showed NDAD candidates to predominantly be middle-class citizens, with no overt mental or psychosocial instability.¹¹ Another study showed that most NDADs were male, white, middle-aged, fairly well educated and generally psychologically stable; only a few had children under the age of 18.¹² Overall, motives for wanting to become an NDAD varied. People wanted to do it in memory of a beloved person who had died; for religious reasons; to publicise organ donation; because they believed it to be the ‘right way’ to grieve; to elevate their self-



■ Altruistic kidney donation – the act of donating a kidney to a stranger without any direct reimbursement – may be difficult for many to understand

esteem; to impress others; to gain media attention; to fulfill a sense of moral duty; or simply to help others to have a life as fulfilled as theirs, thereby giving back to society.¹²

Nevertheless, there is little consensus as to which combination of (reciprocal) motives is acceptable in NDADs, although it is generally agreed that an element of altruism should always be there. Our audit of 25 potential NDADs aims to describe the types of people who volunteer for this ‘gift of life’, the motivations that underlie their actions, and what factors may be considered as precluding potential donors from proceeding.

Current assessment procedure

After the potential NDAD makes initial contact with the transplant unit, information is sent to them in both DVD and written format. If the donor wishes to pursue the option of becoming an NDAD, an appointment with the consultant nurse for the living donor team is made. This appointment is used to clarify any information gaps, discuss motivations for volunteering and explain the process of assessment, including the rationale

Abhijit Nadkarni

DPM MRCPsych MSc
Specialty Registrar,
South London and
Maudsley NHS
Foundation Trust

Patricia Schartau

BSc PhD Medical
student, King's College
London

Lisa Burnapp RN MA

Consultant Nurse,
Living Donor Kidney
Transplantation, Guy's
& St Thomas' NHS
Foundation Trust

Alastair Santhouse

MA MRCP MRCPsych
Consultant in
Psychological
Medicine, South
London and Maudsley
NHS Foundation Trust

for each stage. Initial medical screening – which includes a full medical, social and family history, as well as routine blood and urine tests – may also be conducted at this visit. Alternatively, the donor may choose to return at a later date for further assessment, after thinking about the prospect of donation in more detail.

A letter summarising the consultation is sent to the potential donor's GP, together with a signed consent form for disclosure of information. The GP is asked to confirm the previous medical history and comment on whether they feel there is any contraindication to the donor proceeding if they are found to be suitable. The consultant nurse screens out some potential NDADs with clear medical and/or psychosocial contraindications at this stage, after a thorough discussion with the nephrology or psychiatry consultant.

The rest are referred to the liaison psychiatry team for psychosocial assessments. This is mandatory for all NDADs under the requirements of the Human Tissue Authority. The assessment is carried out by the consultant psychiatrist or specialist registrar, the latter consulting the former if there are any difficulties. It covers a range of domains, including the person's capacity to make the decision after weighing up the risks and benefits; motives for wanting to be a donor (with

the aim of ruling out ulterior motives, like media attention, and unrealistic motives, like salvation); psychiatric or substance abuse history; personal and family relationships;

personal beliefs (including spiritual and religious) and world view; social networks; history of charitable work; and social situation (including employment and financial status), which may be affected by the surgical procedure. An attempt is made to identify any situations where further educational or therapeutic intervention is required before donation to improve potential donors' understanding of the procedure and to avoid any adverse psychosocial outcomes.

After the assessment, the potential donor's GP is contacted to obtain a collateral medical and psychiatric history, and also to seek the GP's opinion on the potential donor's suitability for donation. If there are any complexities that make the decision difficult, a second opinion is then sought from another consultant liaison psychiatrist. Further medical and surgical evaluation of the donor is only undertaken once the psychiatrist confirms that it is appropriate to proceed.

We have analysed data from a single centre relating to the clinical journey leading up to the transplant. Since January 2008, 47 potential donors contacted the department, of whom one did not

Box 1. What data were collected?

Data on the following topics were collected:

- Referral source
- Sociodemographics – including information about age, gender, ethnicity, educational status, employment status and marital status
- Past psychiatric history
- Medical history
- The potential donor's stated reason for wanting to be an NDAD
- What the potential donor hoped to gain by donating a kidney
- Whether the potential donor's GP gave their opinion about the former's suitability to be an NDAD
- Outcome of our assessment – whether the potential donor was deemed suitable and, if not, the reasons for this decision
- Second opinion – whether a second opinion was sought and, if yes, the outcome of this

give any contact details for further follow-up. Of the remaining 46, 19 (41.3%) did not make any further contact, 15 (32.7%) were deemed unsuitable for a variety of medical or psychosocial reasons, six (13.0%) are currently undergoing a work-up to assess their suitability and six (13.0%) successfully completed the process and donated a kidney.

The aims of this exploratory case note audit were to: 1) determine the sociodemographic characteristics and clinical profile of these potential NDADs; 2) determine the reasons for people deciding to be NDADs; and 3) determine the outcomes of assessments performed by our team.

We were unable to find any guidelines in the UK against which to compare our current practice.

Methods

This is a retrospective review of clinical case notes; the data source was the electronic Patient Journey System that is used throughout our trust. The sample for this case note review included all potential non-directed renal donors who were referred to the liaison psychiatry department at a single centre since September 2006. The data were collected between February and March 2011, after obtaining approval from the clinical governance department for the Psychological Medicine Clinical Academic Group of the NHS foundation trust. A data collection tool was designed to gather the information needed to fulfil the aims and objectives of this review. Data were collected on a variety of topics (see Box 1).

Analysis

All sociodemographic, clinical and assessment outcome variables were analysed as categorical

Gender distribution in the sample was almost equal

variables. Age was analysed both as a categorical and continuous variable. All variables were summarised in the form of proportions or means. There were missing data for some variables, as copies of some referral letters and letters from GPs were not available, or information was not obtained at assessment. For those analyses containing variables with incomplete data, the results rely only on the proportion of the sample with complete data for all included variables. All analyses were performed using STATA 10.0 for Windows.

Results

The case notes of 25 potential NDADs were reviewed. Of the 25 NDAD candidates who were referred to our team, 21 (84.0%) attended the assessment appointment. Only data relating to age and gender were available for the non-attenders; 50.0% were male and 75.0% were under the age of 30. Referrals came from each of the three centres in the region, and accounted for 68.1%, 27.3% and 4.6% of all referrals.

Gender distribution in the sample was almost equal – 48.0% of potential donors were female (see Table 1). The mean age was 43 years (standard deviation [SD]=14), with a range of 19–68 years and median age of 46 years; the highest proportion of potential donors fell in the 30–59-year age group (64.0%). Most potential donors (94.4%) were white British, and many had graduate or postgraduate qualifications (47.1%); only 17.7% had no formal qualifications. Forty-five per cent were employed (full or part time), 15.0% were housewives, 10.0% were retired and the rest (30.0%) were unemployed. In regard to personal circumstances, 38.2% of potential donors were either married or in a relationship, while the rest were single or post-marital (divorced, separated or widowed).

Ten (47.6%) of those assessed had a psychiatric history – eight (38.1%) for depression and one (4.8%) for bipolar affective disorder (one remains undisclosed for confidentiality reasons). Nine (42.9%) had a medical history, the most common diagnosis being hypothyroidism (n=3; 14.3%).

Eight potential donors (50.0%, as values were missing for five people) had GPs who communicated their opinion to our team about the potential donors' suitability for non-directed altruistic donation; 61.9% were deemed to be suitable by the liaison psychiatry team. A second opinion was sought in 14.3% of cases. Of the three potential donors for whom a second opinion was sought, two (66.7%) were deemed to be suitable for non-directed altruistic kidney donation.

The reasons for deciding that a potential donor was unsuitable included donor-specific factors –

Table 1. Sociodemographic profile of potential NDADs

Variable (n=25)	n	%
Female	12	48
Male	13	52
Mean age in years (SD)	43 (14)	
Age (in categories)		
≤30 years	6	24
30–59 years	16	64
≥60 years	3	12
Ethnicity		
White British	17	94.4
British Asian	1	5.6
mv	7	
Education		
No formal qualifications	3	17.7
O-levels	3	17.7
A-levels	2	11.8
Graduate	6	35.3
Postgraduate	2	11.8
Other	1	5.9
mv	8	
Employment		
Unemployed	6	30
Employed part time	1	5
Employed full time	8	40
Housewife/husband	3	15
Retired	2	10
mv	5	
Marital status		
Never married	8	38.1
Married	4	19.1
Divorced/separated	3	14.3
Widowed	2	9.5
In a relationship	4	19.1
mv	4	

mv = missing values; NDAD = non-directed altruistic donor; SD = standard deviation

like psychiatric history (current depression, overdoses or self-harming), recent bereavement, non-disclosure of significant psychiatric history, difficult family dynamics or tenuous social circumstances; however, there were also administrative – albeit significant – influencing factors (such as the potential donor not consenting to contact their GP for obtaining collateral history, the assessment being unable to be completed or the GP not responding to the request for collateral information).

The broad positive themes that were identified as being a motivating factor for people wishing to become NDADs included:

- Knowing someone who had donated or received a kidney, or seeing the impact of dialysis on a person's life
- Wanting to make a difference to someone's life
- Wanting to make a contribution, or feeling a sense of duty to society

- History of charitable work, including being a blood donor, being on the bone marrow register and volunteer work
- Spiritual or religious beliefs
- Personal emotional gains, including boosted self-esteem, pride and sense of well-being.

Discussion

In summary, there was an even gender distribution across the potential NDADs. One-third of potential donors were unemployed. The highest proportion were middle-aged, white and educated to graduate level or higher. There was a high lifetime prevalence of psychiatric disorders, the most common being depression. Sixty-two per cent of applicants were deemed to be suitable for donation; one-third of those for whom a second opinion was sought were deemed unsuitable for donation. The reasons for unsuitability for donation were varied and no trend was observed, although common themes were identified among the stated reasons for wanting to be an NDAD.

The literature on non-directed altruistic donation, especially on the characteristics of NDADs, is limited. However, our findings are reasonably consistent with findings from other studies. In a US report,^{1,2} after a preliminary phone interview, 22% of potential donors were deemed ineligible for psychosocial reasons. At the next level of assessment, four of the 51 potential donors were screened out for psychosocial reasons. Of the final 42 who underwent a full assessment, four were ruled out for psychosocial reasons.

Data relating to gender distribution are varied: some studies report a higher proportion of female donors,¹³ others a higher proportion of males,¹² and still further, equal gender distribution¹⁴ – the last being consistent with our findings. However,

what is consistent is that potential donors are overwhelmingly white, Caucasian^{12,13} and middle-aged,^{12,14} which is in line with our findings. A high proportion of potential donors were reported to be married in other studies; this was not the case in our sample.^{13,15} Jacobs *et al* reported that most of the sample were ‘fairly well educated’, had a mean age of 40 years and were largely single, which was consistent with our findings.¹²

Medical and psychiatric history

The lifetime prevalence of any psychiatric disorder was considerably high in our sample. In another study, 16% of potential donors had either past or current psychiatric disorders. Of these, two individuals had remote episodes (that is, they took place more than 20 years ago) of anxiety or panic disorder and depression, and one individual had dysthymia.¹³ On the other hand, Jacobs reported that

of the 22 donors in his study, five had received counselling at some point in their lifetime, five were taking a psychotropic medication, and three were in active therapy for some type of intervention, suggesting a high lifetime prevalence of psychological problems.¹²

NDADs form a small proportion of living kidney donors in the UK, but over the years, the number of referrals we have received has increased. A survey from the USA has shown that, as there is no standardized ‘Samaritan donor protocol’, centres have been developing their own separate protocols.¹⁶ In the UK, too, there is no standard proforma or guideline about how to conduct such psychiatric assessments. It is expected that, as awareness of non-directed altruistic donation increases and the number of potential donors rises, increasingly more psychiatrists in the UK will be called upon to conduct psychosocial assessments of prospective donors. It is important to have guidelines for such assessments, as clinicians in the UK would not have much experience of assessing NDADs; this raises issues relating to ethics, as well as the donor’s psychological status, motives and expectations from the donation, that surpass the standard psychiatric assessment.

Available evidence suggests that psychosocial outcomes are favourable in most directed donors.^{15,17} However, we do not have similar studies in NDADs, in whom there is the added factor of the donor not having the benefit of seeing the beneficial outcome of their act. Longitudinal studies of psychosocial outcomes in NDADs need to be conducted, examining (among other things) any longer-term psychological benefits to the NDAD.

NDADs form a small proportion of living kidney donors in the UK

Key points

- A case note audit was carried out at South London and Maudsley NHS Foundation Trust, with the aim of determining the sociodemographic and clinical profile of potential non-directed altruistic donors (NDADs).
- A high proportion of the potential NDADs assessed – 62% – were deemed to be suitable for donation.
- Standard guidelines need to be developed in the UK that take different centres’ experiences of assessing potential NDADs into account.

Also, psychosocial follow-up of the NDADs should be carried out for a reasonable period of time by a psychiatrist or the GP.

Jacobs *et al* did not find any universally stated reason for wanting to donate, and potential donors often gave more than one reason.¹² This was the case in our experience too – although, as mentioned in the results section, it is possible to identify some common themes. Some of the themes we identified – for example, knowing someone who had received or needed a transplant, a history of medical charitable work, willingness to donate to make a difference to another's life, religious beliefs and a means to boost self-esteem – have been reported previously.^{12,13,18,19}

Conclusions

Most experience in this field is from the USA, and evidence from Europe is limited.^{20,21} Although our sample size precludes larger generalisations, this case note review has been our attempt to disseminate our experience, as we believe we can learn from each other's experiences in this developing clinical field and work towards developing consistent guidelines for evaluation of NDADs ■

Declaration of interest

None declared.

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BritishRenalSociety

Richard Fluck President of the BRS; Consultant Nephrologist, Derby Hospitals NHS Foundation Trust
Jane Macdonald Immediate Past President of the BRS; Assistant Director of Nursing, Salford Royal Foundation Trust

The BRS has just returned from its annual meeting. Held over three days in Manchester, this high-quality event providing education to the multiprofessional team was attended by more than 800 people.

The conference provided ample evidence that multiprofessional research in UK nephrology is active and effective. Improving the care of individuals is the key goal of the BRS. Among many highlights, a few key moments deserve mention.

The BRS inaugurated three named lectures. Sir Netar Mallick gave the first 'Mallick Lecture'. The decision to choose Sir Netar to give the most prestigious of the three lectures was amply rewarded by a *tour de force* talk, which covered the importance of the multidisciplinary team in the history of renal medicine and the NHS in the UK.

The 'Donna Lamping MDT Researcher Lecture' is awarded to a leading proponent of multidisciplinary team research, and was delivered by Joseph Chilcot, Lecturer in Health Psychology at King's College London.

As a considerable surprise, our outgoing president Jane Macdonald gave the 'BRS Macdonald Leadership Lecture'. Jane has been an outstanding president of the BRS, ensuring direction and purpose in the challenging environment of the modern NHS.

This conference also premiered two other new projects for the BRS. This year saw the first of a multidisciplinary team continuing professional development education curriculum as part of the programme. This will continue in future years, and will provide an excellent update for all renal professionals. The Research for Renal clinics were another new initiative launched at the conference. Delegates were able to meet with expert members of the Research for Renal group for one-to-one, in-depth discussions and advice on how to progress their ideas for patient-centred multidisciplinary team research.

Finally, everyone who attended the conference is now a 'virtual' member of the BRS. In the first instance, as a member you will get access to the guest lectures from the conference. We also intend to use this as a means to involve more people in the work of the BRS.

The BRS council would like to thank industry and the attendees for coming; without such support there would be no event. The meeting itself had outstanding content, and there were record numbers of abstracts and oral presentations; this is all due to the programme committee, led by co-chairs Maarten Taal and Sue Cox.

Looking forward, there will be a revised workforce planning document, with consultation via the associations and the members. The publication is due for release in January 2013. The consultation process will be published on our website (www.britishrenal.org).

The BRS continues to be active in responding to the plethora of consultations as the NHS structure (particularly in England) undergoes its transformation ■

BritishRenalSociety 26 Oriental Road, Woking, Surrey GU22 7AW.
 Tel: 01483 764114. Fax: 01483 727816.
 email: brs@britishrenal.org www.britishrenal.org