



Give a Kidney – one's enough Annual Conference following AGM

Saturday 24th March 2018
CZWG Architects, 17 Bowling Green Lane, London EC1R 0QB

Conference: morning session

Andi Ttota - Promoting living kidney donation

AT explained that NHSBT commissioned a survey to gauge awareness levels of living donation. It showed that while 51% of people are aware that a living adult can legally donate a kidney to an unknown recipient, women are more likely to be aware than men (62% vs 55%) and over 50's are more likely to know it's true than those in the 18-24 age group (54% vs 45%).

One in 10 would consider becoming a living donor, although most (59%) only to a family member in need, rather than to a friend (32%) or stranger (11%). There was some variance depending on ethnicity, with black and Asian respondents less likely to donate to a family member (47% vs 60% in white respondents) or friend (29% vs 33% in white respondents), although similar figures when considering donating to a stranger (10% vs 11% in white respondents). (NB if you would like to use these stats in publicity, check first with NHSBT by emailing marketing.comms@nhsbt.nhs.uk)

When promoting living kidney donation, it's important to focus on the following key messages so as to raise awareness, not only of the possibility of living donation, but of how important the issue is:

- You can volunteer to donate a kidney or part of your liver whilst you are alive to help someone in need of a transplant.
- More than 600 people have donated a kidney anonymously during their life to someone on the National Transplant list, alongside many thousands who have donated to a family member or friend.
- Around 5,000 people in the UK need a kidney transplant.
- The average waiting time for a kidney transplant from someone who has died is approximately two and a half years. On average, black and Asian patients wait longer than white patients

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- Living donors contribute two in every 10 kidney transplants across the UK.
- A kidney from a living donor offers the recipient the best opportunity of success
- To find out more visit: www.organdonation.nhs.uk/livingdonation

World Kidney Day is a focal point for charities, when together they can highlight the decline in living donor numbers. They can share facts and figures, while people can share their experience in the media. Social media is very wide reaching and the human stories are very effective at capturing the public's attention, whether a Mothers' Day post about a son who received a kidney from his mother, or brother posting thanks to his sibling as he celebrates his newfound good health. Press coverage of Selena Gomez receiving a kidney from her friend produced a big spike in visits to the organ donor website.

NHSBT has developed the Promoting Donation Hub online, which includes a Living Donor section.

<http://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/download-digital-materials/>

Key contents include:

- FAQs
- Key messages
- Links to leaflets
- Why BAME donors needed
- Links to Transplant TV films
- Social media graphics
- Advice on sharing your story

Promotional items including leaflets, banner stands, A5 flyers, pens and key rings are available for anyone organising awareness raising activities. There were 38,000 unique views of the living donation page over a five-month period.

AT offered suggestions as to how living donors can help:

- Share the Transplant TV films, available through the Promoting Donation Hub
- Share your story on social media, even better with photos
- Put your story forward for a media piece, particularly if you started a chain
- Volunteer to be on an NHSBT poster to promote living donation, if you donated to a stranger
- Break down misconception about living donation – eg posts about the donation process
- Encourage your local hospital to hold an information evening where they invite Trust members to find out more about a subject, or have a stand during Organ Donation Week
- Provide fliers to community venues
- Always direct people to www.organdonation.nhs.uk/livingdonation

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Give a Kidney – one's enough is a registered charity dedicated to promoting non-directed (altruistic) living kidney donation.

Charity Commission Registration Numbers: 1143576 (England and Wales) and SCO45767 (Scotland). HMRC Registered Charity: XT28346

- Encourage people to join the NHS Organ Donor Register at the same time and to talk to their family too!
- Talk to local groups about your experience, eg Rotary, Round Table, University of 3rd Age
- Put yourself forward to be an organ donation volunteer (small pilot ongoing in Birmingham)

NHSBT's organ donation marketing team can be contacted by emailing marketing.comms@nhsbt.nhs.uk

Lynsey Williams - BOUnD study update

The BOUnD study (Understanding Barriers & Outcomes of Unspecified kidney Donation) is a multi-centre prospective study by teams from Plymouth University, King's College London and Guy's and St Thomas'

LW's update details findings from staff interviews conducted by Plymouth University, School of Psychology, qualitative research team: Lynsey Williams, research fellow; Tim Auburn, project lead and Annie Mitchell, project advisor.

Research title: Unspecified kidney donors: barriers and enablers for completion or withdrawal from the donation process. This explores donor services staff attitudes and perceptions of unspecified kidney donors or non-directed donors (NDDs) and donation processes.

The interviews are semi-structured, 30 minutes long, conducted by either LW or Alexis Clarke in 2016, with 60 participants from six donor centres (Bristol, London, Manchester, Birmingham, Plymouth and Leeds).

Participants included 12 Transplant co-ordinators, 10 nursing staff, 8 Nephrologists, 8 Independent assessors, 5 Clinical psychologists, 4 Surgeons, 4 Anaesthetists, 2 Renal live donor co-ordinators, 3 Transplant surgeons, one Pharmacist, one Healthcare assistant, one Laboratory staff and one Administrative staff. The ratio of participants was 34 female to 26 male.

Interview data was transcribed and coded then sorted into themes.

Paper 1 deals with personal and team attitudes to donors, which are marked by polarised descriptions of donors as either 'saints' or 'suspect'. Staff can see the unique benefits to their own working practice of working with this group.

Staff struggle with the word 'altruistic', despite almost exclusively using this term to refer to this donor group. Altruistic status is associated with a 'true' and therefore unattainable characteristic, casting donors in a questionable light. This is despite donors themselves stating they are uncomfortable with the term and staff being aware that this term is not helpful.

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Considering attitudes and perceptions of the whole team working with donors and donation processes, the staff view of the team is differentiated from personal views and is crucial in overcoming individual shortcomings about this donor group and leading to ethical practice. Awareness of how team working harmonises the professional approach to unspecified donation was demonstrated. Reference is made to team relationships in relation to the national scheme; the 'national profile of transplantation' is presented as a foundation for unified team opinion.

Subtheme - demographics: the age of prospective donors, closely related to capacity to consent, is raised by staff in both focus groups and interviews. This predominantly relates to young donors. Discussion of this centres on 'whole team' attitude and is framed as a difficulty for *all* staff that needs resolution in a team context. Shared team discomfort with the age of some donors is described within the context of their role as 'children' and the role of staff as 'parents'. For example *'we all have concern about youngsters coming forward'* when talking about a potential donor in their 20's. Personal discomfort of working with young donors is offset by shared responsibility delegated to the team.

Conclusions - personal views: staff hold polarised and sometimes contradictory views about this donor group. In common with previous research, some staff still view them as 'deviant' in comparison with other donor groups. There are conflicted concepts of the nature of altruism. This accords with previous work which shows scepticism being a feature in relation to unspecified donation, and may point to the usefulness of reducing the use of this term when working with this donor group. However, personal staff views showed the development of positive outlooks. Staff described their own professional journeys and could indicate heightened professional and personal development in relation to more contact with this donor group. Increased exposure reduces the incomprehensibility of the act of unspecified donation for staff.

Conclusions - team views: this study provides an insight into the role of the team in harmonising personal staff views. Confidence was expressed by staff in relation to team working; this was demonstrated by the team resolution of ethical dilemmas. This was explicitly described as an antidote to difficult and conflicted personal opinions. Discomfort with young donors centred largely on the ability to make a reliable decision to consent due to immaturity and restricted life experience. Young donors may also be being considered as 'extended criteria' donors, and as such their motives can be differentiated by staff as subject to increased scrutiny.

Paper 2 deals with staff perspectives about donor families: reporting family attitudes. Staff talked about the importance of family opinions in influencing the decision to commence with donation. The concept of 'unnecessary risk' is highlighted as well as staff perception of family inability to understand motives. The perception that donation is risky is dramatised by using reported speech: *"so presumably what happens is that questionnaire arrives on the desk, the partner looks at it or son or parent or whatever and says, 'What the bloody hell are you doing?'* This shows staff understand the important role of the family in supporting or detracting from progress with donation.

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In contrast to using reported speech a staff member reports what they themselves would like to say to a donor. *'he had his grown up son and daughter with him, and when he went off and they were saying goodbye, you know, they were in tears and I kind of felt 'These are your kids that you are putting through this'*. Family is seen as a mediating factor, encapsulating a reasonable or sensible approach at odds with the more 'reckless' intention of the donor. This highlighted a perception in the staff responses that donation to an unknown recipient is very difficult for families to understand.

In conclusion, family is seen as a mediating factor, offering a more reasonable or sensible approach. Reporting hypothetical speech, or voicing their concerns, shows a personalised response by staff to their perceptions of how family members feel about the donors' intentions. It is not just what staff say about family members, it is *how* these opinions are expressed.

Future directions and research will include further data analysis and dissemination of staff interviews; completion of donor interviews - currently 26 out of 45 are completed and there are difficulties with collecting the full set for medically and self-withdrawn donors, who are less willing to contribute to the research; analysis of the entire data set, with manuscripts and publications; feedback of results to research participants.

LW wanted to express thanks to Alexis Clarke who worked to develop this research and to the BOUnD team at Guy's.

Bob Wiggins & Kiran Gupta - Two personal stories

BW opened with a reminder that today's conference is about variations between donors' experience. Although the first co-ordinator BW spoke to was not at all welcoming, he did go on to contact a second transplant centre instead and from then on had a very positive donor journey.

Although KG considers donation the best thing she has ever done, she feels the process could have been easier. She also regrets that due to timings, she couldn't take part in the paired / pooled donation scheme.

Being under 40 and from an ethnic minority, KG is an unusual non-directed donor. As a single person without close family, KG did not have any dependents to take into consideration when deciding to donate.

KG was pleased to discover Give a Kidney's website through organic search and found the information there useful. She also found the Nephrology Consultants and Surgeon helpful and informative. Medical assessments passed smoothly and surgery and recovery went well.

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However, where KG felt let down was with the lack of communication, support and flexibility from the hospital and particularly with poor interactions with the living donor co-ordinator.

Although not expecting special treatment, there was a lack of acknowledgment and appreciation and she actually felt she was treated with suspicion. Instead, taking the lead from blood donation centres, KG believes that, for example, every altruistic non-directed living donor should receive the silver pin from NHSBT automatically, instead of that recognition only being triggered by individual hospitals submitting the request to NHSBT.

There was no flexibility around appointments and no communication about timescales or where she was in the process. Establishing a good rapport with the living donor co-ordinator is important and donors shouldn't have to chase for information. For example, co-ordinators could share a variety of case studies (with a range of gender, ethnicity and age), video clips and other information.

KG also suggested a network of non-directed altruistic living kidney donors could be set up to talk on the phone or even meet up with prospective donors. Consideration should be given to when directed and non-directed donors should be treated differently eg. communication tones, appointment scheduling, timeline for the process as a whole. Could tests be arranged more flexibly or locally, which might speed up the process? Perhaps it could be possible to have the surgery itself at a different hospital (if the donor has family in another part of the country who will be supporting their recovery), but have all the outpatient pre-op assessments and post-op follow-ups done locally to the donor's home or work. In order to achieve greater consistency in treatment of different types of living donors, KG suggests that all living donors should be required to have a psychiatric evaluation - not just NDDs - and at a much earlier stage in the process, before the full medical work-up and extensive tests are completed.

KG also believes that NDDs should not automatically have to wait for their case to be assessed by a panel of three HTA Board members. Instead, as with other living donors, the Independent Assessor should be able to recommend approval in their report to the HTA, and HTA staff can give formal written approval, without needing to wait for the HTA panel to meet.

These are important considerations, particularly if we are to encourage younger and more ethnically diverse groups of non-directed altruistic donors, whose lives may be in flux and are more 'mobile', as opposed to older, more settled, retired and financially well-off donors.

Conference: afternoon session

Aisling Courtney – the Belfast Brand of living donation

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AC has worked at the Royal Free in London, Beaumont Hospital in Dublin and now Belfast. About 90 – 95% of her work now is transplantation, because of the transformation it makes to a life compared to being on dialysis.

The population is 1.8m in Northern Ireland, with just one transplant centre. In 1999 there were one living kidney donor transplant, in 2008 there were nine, but then numbers increased. There were over 70 in 2016, and there have been 33 non-directed donations.

Previously, it was hard to donate, donor work-up taking 18 - 24 months, with a long time between tests and a high drop-out rate.

Now there's a much shorter, streamlined process.

An information pack is sent out to enquirers, with a health questionnaire on an A4 sheet. We know that education and low literacy can be a barrier, so the six pages that some centres have is too long. A series of questions such as: 'Have you been diagnosed with high blood pressure / kidney stones / cancer' and: 'do you smoke?' allow for initial screening.

The questionnaire can then be reviewed alongside the electronic care record. The prospective donor then has seven of the 10 steps in the process all on the same day; it starts with them seeing the Co-ordinator and finishes with the nephrologist who is able to give them a lot of the results and whether they are look to be suitable to go further (on 'amber') or if they are unsuitable to be a donor ('red'). By the end of that first day, they will have a good idea of progress and timing. The wider team, including the surgeons, then discusses each person's assessment, then donor and surgeon meet.

From March 2010 when the one-day assessment was introduced - a multi-disciplinary meeting, then surgical assessment - 70% of prospective living donors go on to donate. As a result, dialysis has declined, having risen steadily,

There are variations in pmp numbers across centres, but Belfast is at 41.6pmp, much higher than every other country in the UK.

When considering treatment decision making, belief determines how we behave. The Physician has to believe that living donation (LD) is the best form of treatment and leads to better outcomes, and secondly to believe that LD is safe (although there can never be zero risk, it is a low risk process). Patients beliefs are influenced by the information they are given, and their decision to donate is also influenced by contextual factors - so we need to make it as easy as possible for people to donate. We also need to look after donors so that they have a positive experience. They are ambassadors and will lead to donation becoming a cultural norm.

Although there are reasons why Belfast donations should be so high in number (predominantly white population, cohesive communities etc.), the donation rate there

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far exceeds other UK centres. LD activity has plateaued, and there is still a long way to go before people are no longer dying while waiting for a transplant.

Maximising the use of pairs and chains ensure that the maximum number of patients benefit from a living donor. The goal is for all altruistic donors donate to a chain, which is feasible if they start off with a clear timeframe.

We know what doesn't work: lack of knowledge, making it hard to donate, with health professionals giving mixed messages. We continue to seek ways of maintaining excellence and appropriate staffing.

Panel Discussion

What can we do to reduce variation and improve the system?

Belief and trust as a donor is crucial. One person sees all donors in Belfast. This person needs to be enthusiastic about living donation, not risk-averse, someone who will inspire confidence and see them through the process.

We can't influence the infrastructure but we can influence belief. We need to educate others, help them to see that giving is a healthy thing to do, not strange. Also to understand that recipients are often conflicted and feel guilty. There needs to be a shift in mind-set so that the donor is seen as part of the recipient's team.

We need to look at pathways and ask, is every step donor friendly? Donors should be asked to come back and say if the team is not meeting expectations eg. unclear timeframe, lack of communication as to where they are in the process. Clinicians need to stop putting NDDs at the bottom of the list, because they don't have a recipient attached.

There are 23 transplant units and over 75 renal units, with each transplant unit governed by its own NHS Trust.

A few years ago, there were no campaigns for living donation, but there's been a real shift in the past 18 months so that now they are an essential part of NHSBT's campaign for organ donation.

The charity can play a role in the psycho social process that will bring about cultural change. Some clinicians had to be convinced. Living donation is cheaper in the long run, so resourcing should not be an issue.

Some past NDDs might help with mentoring, where co-ordinators are open to that kind of collaboration.

The charity will continue to send a supply of leaflets to all the transplant centres once a year.

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Will opt-out make a difference? Although it won't lead to there being enough organs from deceased donors to meet the need, the important thing is that it promotes discussion and leads to better education around organ donation.

Lisa Burnapp – update from NHSBT

Last year saw the highest number of deceased donors in the UK: 1,413, resulting in 3,710 transplants. Since 2007/8, there has been a 17% decrease in waiting lists, a 75% increase in transplants (all organs) and a 56% increase in deceased organ donors.

Kidney transplant rates (deceased and living) are at 51.1 per million population (pmp), placing them fifth in Europe, Australia and the USA for 2016 (behind Spain, USA, The Netherlands and France). Deceased donors only are at 21.5pmp and place the UK eighth, but where only living donors are considered, they are at 15.6, placing the UK fourth.

The increase in deceased donation activity is likely to have an impact on living donation by influencing the decisions patients make as well as the conversations that medical teams have with patients about their choices for transplantation. The ambition of the Living Donor Kidney Transplant (LDKT) 2020 Strategy Implementation Group is to achieve, by working together with all stakeholders:

- The best outcome for every donor and recipient
- More successful transplants for more people
- The right transplant at the right time
- The most of every transplant opportunity, every time
- Equity of access

Success by 2020 will be measured as follows:

- We'll see an increase in LDKT activity and state of the art donor care, with a rate of 26pmp (in 2017 it was 15.6pmp)
- The principle of 'transplant first' will be embedded, with improved equity of access to LDKT; 50% of patients having a pre-emptive LDKT (in 2017 it was 42% and the trend is increasing)
- Ensure the UK Living Kidney Sharing Schemes (UKLKSS) are clinically and cost effective, with 75% of identified transplants proceeding (it was 59% in 2017 and the trend is increasing)

Despite the increase in deceased donation activity, living donors still made up 42% of all donors in 2016/17.

Projected activity was 116 LKD transplants per month (21pmp) for the current year, but the average in year is 85 per month and 15.6pmp.

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There is a wide variation in the numbers of non-directed donors (NDDs) across transplant centres, with some hospitals donating more kidneys into the pool, whilst others receive more from the pool. This is partly due to the make up and proportion of patients on the transplant waiting list for each centre but may also suggest different approaches and donating behaviours in different parts of the country. Addressing this variation is a key priority for the LDKT 2020 implementation group. Numbers of NDDs were 87 in 2017, which is stable in comparison with last year but down from 107 in 2013, 110 in 2014 and 94 in 2015.

Until now, there has been a choice of donation pathways for NDDs: direct to the waiting list, into a short chain (from 2012) or into a long chain (from 2015) with the UK Living Kidney Sharing Scheme (UKLKSS). However, a match for a high priority patient on the waiting list always takes precedence. From 2018, the default pathway is into a chain. The aim is for 75% of NDDs to donate into a chain (currently 25%) so that up to 2-3 more recipients benefit from each donation.

By December 2017, 635 living donors had led to 791 transplants, with the additional 156 transplants resulting from chains. As transplants in the kidney sharing scheme have increased and outcomes are so good, the need for incompatible living donor kidney transplants has declined and the numbers have decreased since 2011. There is some work to do and NHSBT hope to make it easier for people to give and to receive a kidney by:

- Creating a culture of living donation
- Making donors and recipients ambassadors of the future
- Working together to share and embed best practice
- Improving data collection, reporting and dissemination
- Informing patients and public; understanding recipient views and choice
- Maximising the kidney sharing schemes
- Getting investment right

An All Party Parliamentary Kidney Group (APPKG), driven by the National Kidney Federation, met in November 2017 and published a manifesto and resulting recommendations, to be incorporated into LDKT 2020 implementation action plans.

We know it doesn't work if people don't know what choices they have, or if it's too difficult for donors and recipients to seek advice. Healthcare professionals giving mixed messages and delays in the donation pathway contribute to a lack of success.

LB highlighted the following resources for anyone helping to raise awareness and looking for information:

- NHSBT - www.organdonation.nhs.uk/about-donation/living-donation/
www.odt.nhs.uk/living-donation/
- NHS England
 - www.england.nhs.uk/publication/commissioning-policy-reimbursement-of-expenses-for-living-donors/

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- Living Donation – other UK Countries: Scotland, Northern Ireland
 - www.organdonationscotland.org/tell-me-about-living-donation
 - www.donatelife.co.uk
- NBTA Living Transplant Initiative
 - www.nbta-uk.org.uk/living-transplant-initiative/
- British Transplantation Society- UK Guidelines
 - bts.org.uk/guidelines-standards/
- KQULP, 'Transplant first'
 - www.thinkkidneys.nhs.uk/kquip/

LB also highlighted a study on 'Relinquishing anonymity in the UK' carried out with The British Transplantation Society (BTS) – see poster attached.

Anonymous living kidney donation is carried out in a limited number of European countries such as the UK, the Netherlands and Sweden. The UK differs from other countries in that the donor and recipient may meet one another after the operation.

Findings of this exploratory study support the option of voluntary contact and the potential to meet after anonymous living donor transplantation, however the option to meet in person is not widely utilised.

Dutch and Swedish participants reported being generally satisfied with anonymity; there were very few accidental meetings, the desire to meet was low, although desire to know was higher. The majority felt that the decision to risk the negative consequences of a meeting should be their own.

As for the UK, the number of actual meetings was low (3%) although contact was 10%, so the option to meet in person was not widely used. Satisfaction with non-anonymity was high. These findings support the option of voluntary contact.

Summary and close

Chair BW concluded the day by thanking today's speakers for so very kindly giving up their Saturday to join us.

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