Altruistic kidney donation: mental health assessment - new guidance

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“Altruistic” organ donation

• Aka: non-directed, stranger, anonymous, unspecified & "Good Samaritan" donation.

• Not possible in UK until Human Tissue Act 2004

• Act doesn’t specify organ
  – liver: few so far
  – lung: none so far

• 2012: directed altruistic donation
Number of altruistic kidney donations in the UK: 463 (by end Dec '15)
Altruistic kidney donation: UK numbers

• Slow start 2006-2010: 6 in first year
• Rapid increase 2010-2014: 118 in 2013/2014
• Now levelling off at 100/yr - or beginning to fall?
• 10% of all live donation
• More than other countries
• More than expected (double)
• Broadly accepted by transplant community
Give a Kidney
one's enough
Initial arrangement

- Donor approaches transplant centre
- Initial assessment by co-ordinator
  - Health questionnaire
  - GP info
  - Baseline bloods
- HTA-mandated referral to psychiatrist
  - BEFORE any invasive investigation
Former HTA Guidance for transplant teams and Independent Assessors

• In cases of non-directed altruistic donation, as well as medical and surgical assessment, psychiatric assessment is a necessary part of the process to ensure fitness to donate (‘work up’).

• It is the responsibility of the transplant team to arrange this. Early psychiatric assessment is recommended to ensure there is no relevant psychiatric or psychological illness.

Para 51
Former HTA Guidance for transplant teams and Independent Assessors

The IA must:

“Be satisfied that the donor has no evidence of current or past mental illness that affects their ability to donate altruistically with full, informed consent.”

Para 93
HTA Guidance: problems

• Specified “Psychiatric” assessment
  – as opposed to psychological
  – referred solely to mental illness
• Said nothing about how to assess
• Very general about the purpose
• Was NOT based on any provision within the law or linked regulations
Previous Process

• Transplant co-ordinator refers to psychiatrist.
• Psychiatrist reports back:
  • No C/I:
    – donor gets worked up
    – Psych report goes to IA (NOT HTA) before transplant approved
  • Psych C/I:
    – No standard process
      • Inform GP?
      • Inform Psych services?
      • Donor free to approach other centres?
Problems in previous system

• Yes/No decision expected from psych
  – No room for “yes but…”
• No standardised approach to assessment
• No central collation of psych reports in those approved
• NO collation (central or local) of psych reports in those not approved, so we simply don’t know
  – Numbers
  – Reasons
  – Outcomes
• Donor objections (“worse than the angiogram”)

Process reviewed

• 2012: HTA issued revised guidance
• New Category:
  • DIRECTED ALTRUISTIC DONATION
• Mainly to reduce risk of concealed reward in new category
• Enhanced IA
• “probe body language”
Living Organ Donation - Key changes

- Enhanced IA assessment for certain categories of cases
  - Directed altruistic – esp. Due to third party arrangements
  - Economic dependence – outside of familial
- Signed donor declarations
- New referral requirements linked to the Organ Donation Directive
- Removal of six month rule for IA reports
- Removal of our psychiatric report requirements
- Removal of our anonymity requirements in altruistic and paired/pooled cases
DIRECTED ALTRUISTIC DONATION:
HTA requirements

- Psych assessment **not** required
- Enhanced IA assessment **is**
- HTA approval via panel, not staff
Enhanced IA

- One per centre.
- IA with additional training
- “Body language prompting probing interview”
- Very few IAs are mental health professionals
- Focus is NOT motivation but uncovering reward, coercion or duress.
Current position: more kidneys, less clarity

- HTA does **not** mandate psych assessment by mental health professionals in non-directed altruistic cases.

- HTA **does** mandate quasi-psych assessment by non-mental health professionals in directed altruistic cases.

- BTS, NHS-BT, WHO and CoE **do** expect psych assessment in non-directed cases.

- But do **not** clarify
  - content
  - process
  - focus
  - range of outcomes.
• Guidelines for the Psychosocial Evaluation of Living Unrelated Kidney Donors in the United States

• M. A. Dew, C. L. Jacobs, S. G. Jowsey, R. Hanto, C. Miller, F.L. Delmonico

DOI: 10.1111/j.1600-6143.2007.01751.x

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Process

• Initial screening
• Mandatory 2-stage evaluation by independent clinicians
  – Stage 1: SW, nurse, AHP
  – Stage 2: Psychologist/psychiatrist
• Interview with donor’s NoK
• 2/52 “cooling off” period
Risk factors

• Past psych history
• Current psych symptoms
• Substance misuse
• Financial pressures
• Limited capacity
• Ambivalence
• Self-directed motives (*Incl relief from guilt*)
• Stressors
• Poor support
• Secondary gain
Consensus workshop: 2015

- 60 MH professionals from UK & Ireland
- Psychology = psychiatry (plus CNS, TxC, SW)
- Considered draft document - 9 questions
- Answers debated, revised
- Circulated afterwards & further revised
- Confirmed content
- Submitted to BTS - adopted
- Will be in next UK guidance
Mental Health Assessment of Altruistic Non-directed Kidney Donors

Consensus Guidance Statement.
EAPM special interest group in transplant medicine
EAPM meeting, Nuremberg, Germany, July 2015

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1. Which potential donors should be referred?

- **RIE position (post 2012):**
  - under 30
  - over 70
  - history of contact with mental health service
  - treatment with psychotropics in primary care
  - psychological symptoms at initial assessment
  - GPs expressing concern
1. Which potential donors should be referred?

ALL of them
2. Who should do assessments?

- Any suitably qualified mental health clinician

- who is sufficiently familiar with transplant procedures, risk and outcomes.

- Centres with access to more than one type of clinician can direct referrals accordingly

- Some cases may require assessment by more than one professional.
3. At what stage of work-up?

- **after** initial screening and clinical assessment by the transplant team
- **before** any investigations which carry risk
4. With what information?

- A clear description of the reason(s) for referral
- Details of past episodes of M/H treatment
- Supplemented by M/H assessor’s enquiry
- Potential donors informed by referrer
5. Purpose of assessment?

- To confirm capacity
- To explore motivation
- To explore resilience and available support
- To explore expectations
- To identify additional risks
- To clarify routes to follow-up
- To exclude from donation
6. How should it be undertaken?

Tailored to:

- referral question
- clinical circumstances
- professional background of the assessor

- Essential in all cases: clinical interview

- Additional elements as appropriate:
  - Repeat interviews
  - third party interviews
  - standardised questionnaires
  - structured assessments
7. To whom should the report be sent?

- the referring clinician in the transplant team
- the GP
- any relevant mental health services
- the patient?
- forwarded to the HTA-IA?

- The patient should consent
8. Follow-up requirements

- Assessors should identify routes to M/H follow-up of those who may need it after donation
  - short term
  - long term

- For would-be donors declined on M/H grounds:
  - direct liaison with relevant M/H services
  - & GP
9. Should reports/data be collated routinely?
   What’s in the core data set?

Agree a minimum core data set