Psychosocial Dilemmas in Live-Related Donation

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24th May 2008
Overview

- Patient pathway and psychosocial assessment at GOSH
- Psychosocial implications of consent
- Psychosocial factors and their impact on the decision to donate
- Our psychosocial assessments and useful ways of working
Numbers of Renal Transplants

2006-7

- 22% (N=29) of all paediatric transplants, UK
- 31% (n=16) of all live-related paediatric transplants, UK
- 17% (n=13) of all cadaveric paediatric transplants, UK

- Live donation is clinically very successful
- Raises psychosocial dilemmas
Patient Pathway

End-stage renal failure (+ dialysis)

Referral for psychosocial assessment
(Family Therapist 0.3WTE, Nurse Counsellor 0.5WTE, Social Worker 1.0 WTE & Psychologist 0.4WTE)

Live-related ‘on-call’ for cadaveric
Consent
(Human Tissues Authority, UK, 2006)

- Mental capacity
- Voluntary decision without "undue pressure"
- Full information on the procedure and risks
- Continuing dialogue – consent as a process
- In the UK the autonomy of the patient is valued in making healthcare decisions
Informed Consent from a Psychosocial Perspective

- Informed consent usually medically defined
- How can we help donors and recipients to make informed choices about psychosocial risks and benefits?
- Decisions impact on identities and family relationships, now and in the future
What is “undue” pressure?

- Donor medically assessed in adult hospital (separately from child), but psychological assessment not offered routinely
- Context of medical ‘best interest’, societal expectation, parental wishes, strong live donor programme within unit
- Very difficult to define “undue”!
What is “undue” pressure?

Continued

- Double-bind – if they say “no” they may experience regret and guilt and if they say “yes” they may regret the decision and resent feeling pressured (Franklin & Crombie, 2004)

- Does the joint welfare of the family outweigh the interests of the donor as an individual?
Broad Context Influencing Live Donation Decisions

- Cultural norms and expectations of the recipient donor relationship (Nolan, 2004)
  e.g. Japanese – gift giving and reciprocity

- Spiritual / Religious beliefs

- Relationship to transplant team – trust (Nolan, 2004)
Factors Influencing Live Donation Decisions

- Closeness of donor-recipient relationship influences attitude to donation and outcome
- Gender and willingness to donate
- Societal construction of motherhood
Factors Influencing Live Donation Decisions Continued

- Role conflict for mothers – care for child in hospital vs. donation
- Financial impact of live donation – differences in parental income
- Nature of renal disease - timing
- Multiple children in the family in need of transplant
- Shortened life-expectancy and global learning disability
Family Dynamics Around Live Donation

- Separated parents
- Adoption
- Child Protection – abuse or suspected abuse history
- Professional beliefs and differences
- Deciding to donate motivated by compensation for past family wrongs (Corley et al., 2000)
Psychosocial Issues Arising from the Decision Making Process

- Parental mental health – continuum from lifestyle behaviours to clinical levels
- Medical workup – uncovered health problems - equivalent to paternity test

Feinstein et al., 2005:
- Highest in adolescents responsible for their own medications who received cadaveric transplants
- Significantly lower after live related donation
Franklin & Crombie (2003)

- Two qualitative studies (N = 50 interviews) including parent-child pairs
- Explored: decision to donate, relationships, experiences and beliefs pre and post transplant
- Analysis: content, thematic and interpretative with independent rater validation
Results

- Parents donated “out of love – it was the natural thing to do”
- Parents said they had become closer after donation but half said they had experienced some form of conflict.
- 4 adolescents expressed a sense of obligation but preferred the transplant to dialysis, although said cadaveric donation may have been better from a psychological perspective.
- Where relative had elected not to donate this disrupted family dynamics - with resentment and disappointment expressed by potential recipients.
Adolescent Quotes on Live Donation

“... would have liked to have refused but that would have caused so much conflict......I knew what it would be like afterwards – eternal gratitude....He never lets me forget like the child who has to be obedient as if I can never be grateful enough.”
“No one really asked me – it just happened and I never really liked him that much. Afterwards I hated the idea I had his kidney inside me. It took me a long time to adjust and even now I wouldn’t mind too much if it rejected and I could have one from a stranger”. 
Discussion & Conclusions

- Importance of the success of the transplant in making sense of the experience
- Importance of closeness of relationship and seeing the person suffer first hand
- Decision to donate from parents appeared immediate and altruistic with some fathers expressing a degree of ambivalence
Psychosocial Family Preparation Meeting

- Fear of needing to “pass” potentially undermining open communication
- Informed by systemic ideas

**Family structure** - genogram
- **Mapping the network** and relationship to / experience of healthcare professionals
- **Family relationships** e.g. challenge of illness to parenting / maintenance of “normal life”
- **Family’s story of child’s illness** – e.g. coping strategies, influence on family life past and present
Psychosocial Family Preparation Meeting *Continued*

- **Future treatment plans** including understanding of medical plans & informed consent
- **Profile of child** – developmental history, educational achievement, behaviour, emotional needs, understanding of their condition
- **Profile of siblings** e.g. adjustment, understanding of illness
- **Practical plans and preparation** e.g. care of siblings
Psychosocial Family Preparation Meeting *Continued*

- Report summarising meeting circulated to family and team

- Recommendations including further psychosocial input / assessment
Helpful Ways of Working

- Transitions
  (e.g. loss of haemodialysis routine and social support)
- Joint working and seeing child and parents separately
- Psycho education
- Normalisation – permission giving
- Externalising
Helpful Ways of Working

Continued

- Therapeutic use of genograms

- Interventive, relational questioning including hypothetical and future-orientated questions
Future Developments

- Paired donation
- Blood group incompatible donation
- Resolving some dilemmas and creating new ones
References


• Human Tissues Authority. Code of Practice – Donation of organs, tissue and cells for transplantation. Code 2 July 2006 – available online

Thank You for Listening!

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