



Psychosocial Dilemmas in Live-Related Donation

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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)

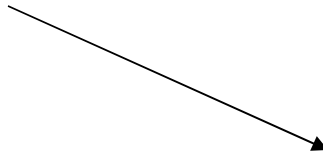


Referral for psychosocial assessment

(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

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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.”**

Adolescent Quotes on Live Donation *Continued*

- **“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

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Thank You for Listening!

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