Making difficult decisions together…?

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Outline

- Decision making
- Abstract
- Real life - case studies
- Discussion

Decision Making Continuum

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Background

- Prior to 1990s an intellectual (learning) disability excluded people from organ transplant
- Rationale: they lacked the necessary cognitive skills to comply with the complex post-tx medication regimes
- Strong pull to allocate organs based on QoL. People with LD were *presumed* to have poor QoL

(Martens et al 2006)

Background

- Moved more to a stance that each case must be decided on an individual basis and not on a group characteristic such as presence of LD (e.g. Whitehead, 1998)
- There is very little research on LD and Tx and outcomes

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Studies

- Benedetti et al (1998) 8 out of 1271 kidney transplants were to people with IQ<70. 100% patient and graft survival at 1 and 5 years. 1 patient died at 10 years.
- Acceptance criteria: i) cooperative patient, ii) reliable long-term caregiver, iii) long life expectancy, iv) able to take meds under supervision.
- Carers all reported improvement in patients' QoL post-tx but not formally measured.

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Benedetti et al (1998)

- Conflict between doctors duty to the patient and society's need to maximise the use of finite resources
- Limited organs => difficult choices
- Pressure to select good risk recipients to optimise outcome statistics

- *Question: Is this so relevant in the case of living-related donations?*

Martens et al (2006)

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- Reviewed the accessibility and outcomes of organ tx in people with LD
- Concerns re possible lack of access but lack of info
- Only 6 centres had published outcome data on renal tx. Also 1 from personal communication.
- 1 yr & 3 yr survival rates = 100% & 90%
- Good adherence with meds due to family/caregiver support
- Warn about publication bias

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Read (2011)

- Unpublished Thesis
- Qualitative analysis of consultants' and carers' views of how adults with LD cope with End-Stage Renal Failure
- 5 adult patients LD ranging from mild to severe
- 4 on haemodialysis, 1 about to start
- 1 patient Tx, 1 patient had 2xTx, 1 deciding

Read (2011) Themes

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Consultants:

- Feeling of increased responsibility re: decision-making
- Importance of family's ideas
- Intricacies of trying to predict how someone will fare with a treatment option

Families:

- Less talk about decisions, more focus on Patients' experiences of treatment

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What shapes our decisions?

- Disability Acts prevent discrimination from a legal point of view
- But there remains concern that institutional discrimination occurs (e.g. Death by Indifference, MENCAP, 2012)
- Do our beliefs impact upon the decisions we make regarding appropriateness of transplant as an intervention?
- Risk vs benefit analysis

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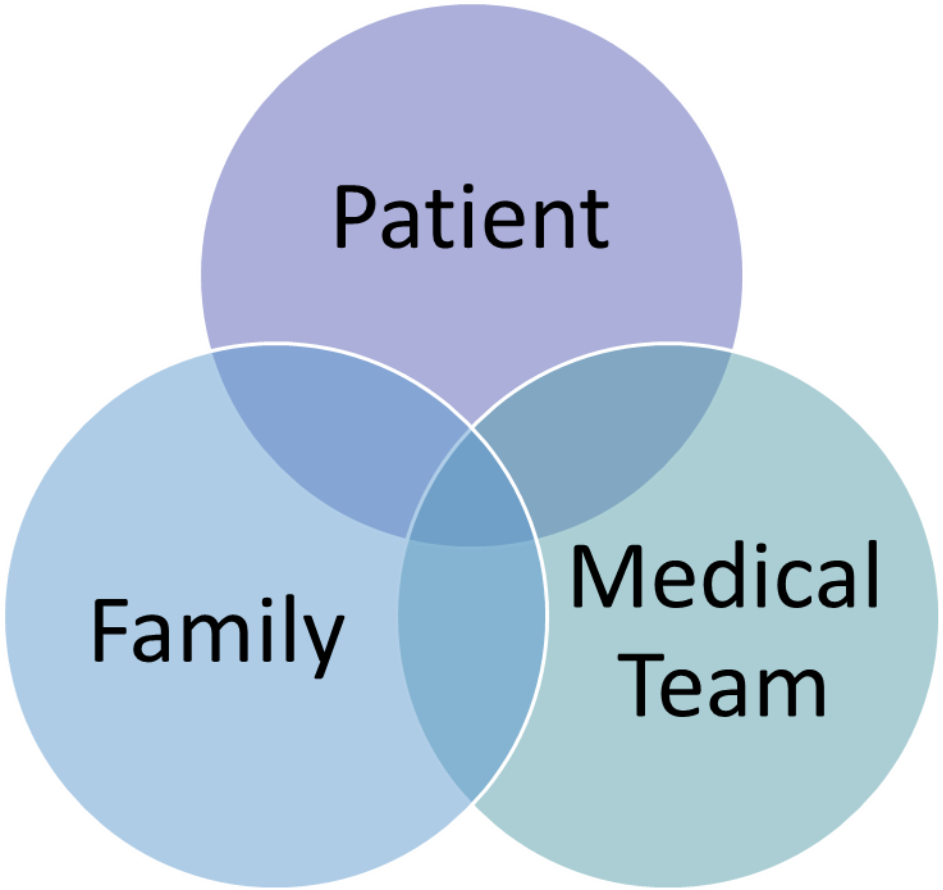
Dynamics of Decision Making



Patient Factors

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- Understanding
- Illness experience
- Coping (mood & behaviour)
- Experience of adapting to change

Family Factors

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- Journey so far (good experiences and challenges)
- Do parents have same view or different?
- Supported by extended family or not?
- Beliefs – cultural and religious
- Hierarchy of Need

Medical Teams

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- What are the options available?
- Specific medical considerations
- Predictions about how the young person & the family will cope with each different treatment
- Ideas about QoL
- Differing opinions between team members
- Experience of past decisions with other families

Cognitive biases

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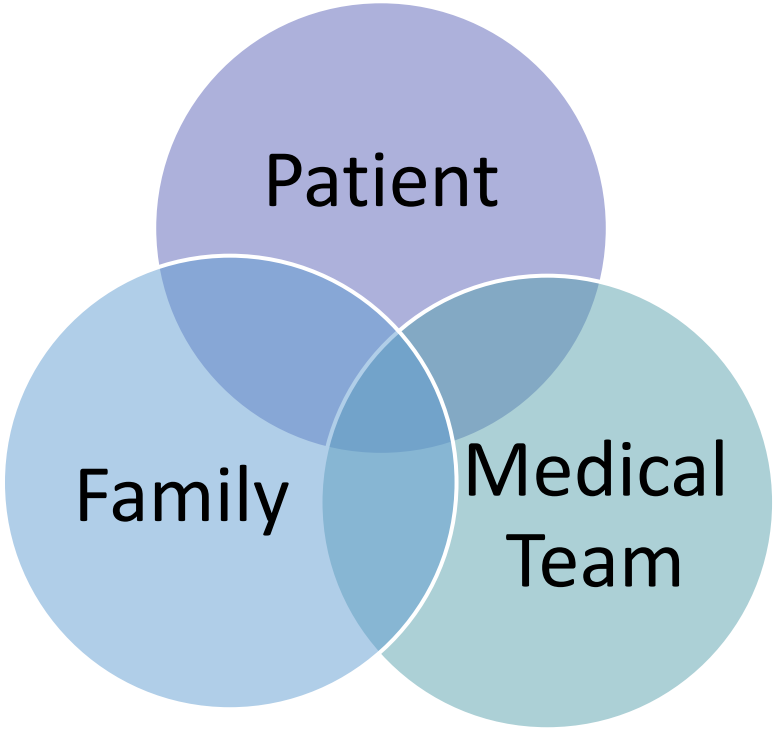
- QoL in Adults: Individuals > Family Members > Health Professionals (e.g. Crocker et al., 2015)
- Why? Outsider vs insider perspectives (Longmore, 1995)
- 'Outsiders' latch on to a single trait (e.g. the disability or health condition)
- 'Insiders' take into account their full range of experiences.
- Improve clinical decision making: professionals should defer to the views of close family members, when psychological and social QoL are under consideration (Crocker et al., 2015)

Dynamics of Decision Making

Health Journey

- Information
- Understanding
- Discussion with others
- Feelings of control
- Beliefs
- Predictions



- Cognitive biases
- Assumptions
- Judgements
- Beliefs
- Emotions

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GOSH

- 3 children in ESRF with severe LD
- All with no or little language

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Child M

- Severe LD, tuberous sclerosis & epilepsy
- No language
- 15 years old
- Family & medical team in similar position
- Proceed with living-related donation
- PD, Nephrectomies, then HD following peritonitis
- Anxieties about tube-pulling, but coped well with PD and HD and transplant
- Doing well

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Child A

- 6 years old
- Multiple & complex medical problems
- Not currently on dialysis
- Family clear want to proceed to transplant
- Ethics committee
- Dad happy to donate
- Family feel they have to explored every aspect (religious influence)
- Medical Ambivalence?
- Differing perceptions of health journey between family and medics (e.g. medics = risky, family = we live with risky).

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Child R

- 11 years old
- Posterior urethral valves
- Autistic Spectrum Disorder & limited language
- Quite active
- Struggles with injections (e.g. immunisations)
- Dislikes but tolerates bloods
- No living related donor
- Single Mum, rest of the family in Zimbabwe
- Will he cope with dialysis? Will be cope with transplant?

What to families need to make decisions?

- “someone to guide them, but within a relationship of trust” (MacKean et al., 2004)
- Jackson et al. (2008) Review of 149 studies:

1) Timely, consistent, up-to-date, evidence-based information tailored to the individual, delivered in a variety of formats from trustworthy sources.
2) To talk with others in the same situation to share information, experiences, and ideas.
3) To be in control of one’s level of preferred level of involvement in the decision-making process.

What do we need for shared decision making?

- Develop a partnership
- Have an understanding of patient's preferences for information
- Identify choices
- Present evidence
- Help patient reflect on and assess the impact of alternative decisions with regard to values and lifestyle

(Towle & Godolphin, 1999)

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What do *we* need for shared decision making?

- Adding to the evidence-base: need to follow-up children with LD post-tx and their parents/caregivers & publish case studies
- Being aware of our own beliefs, assumptions, potential biases & how they influence our behaviour
- Try to understand a family's beliefs, assumptions, potential biases and how they may influence their decision-making

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Discuss……

References

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