

# Making difficult decisions together...?

EWOPA 9<sup>th</sup> September 2017

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# Outline

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

# Decision Making Continuum



# 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

# 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.

# 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)

- 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



# 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- Unpublished Thesis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

## 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

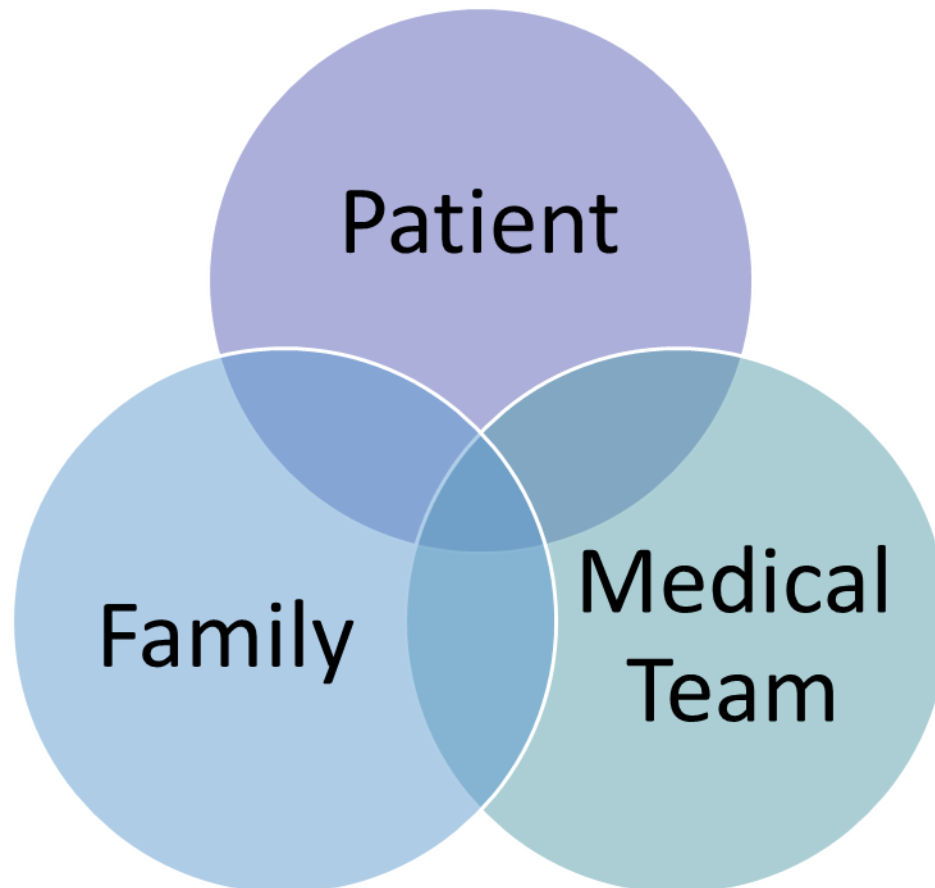
## Families:

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

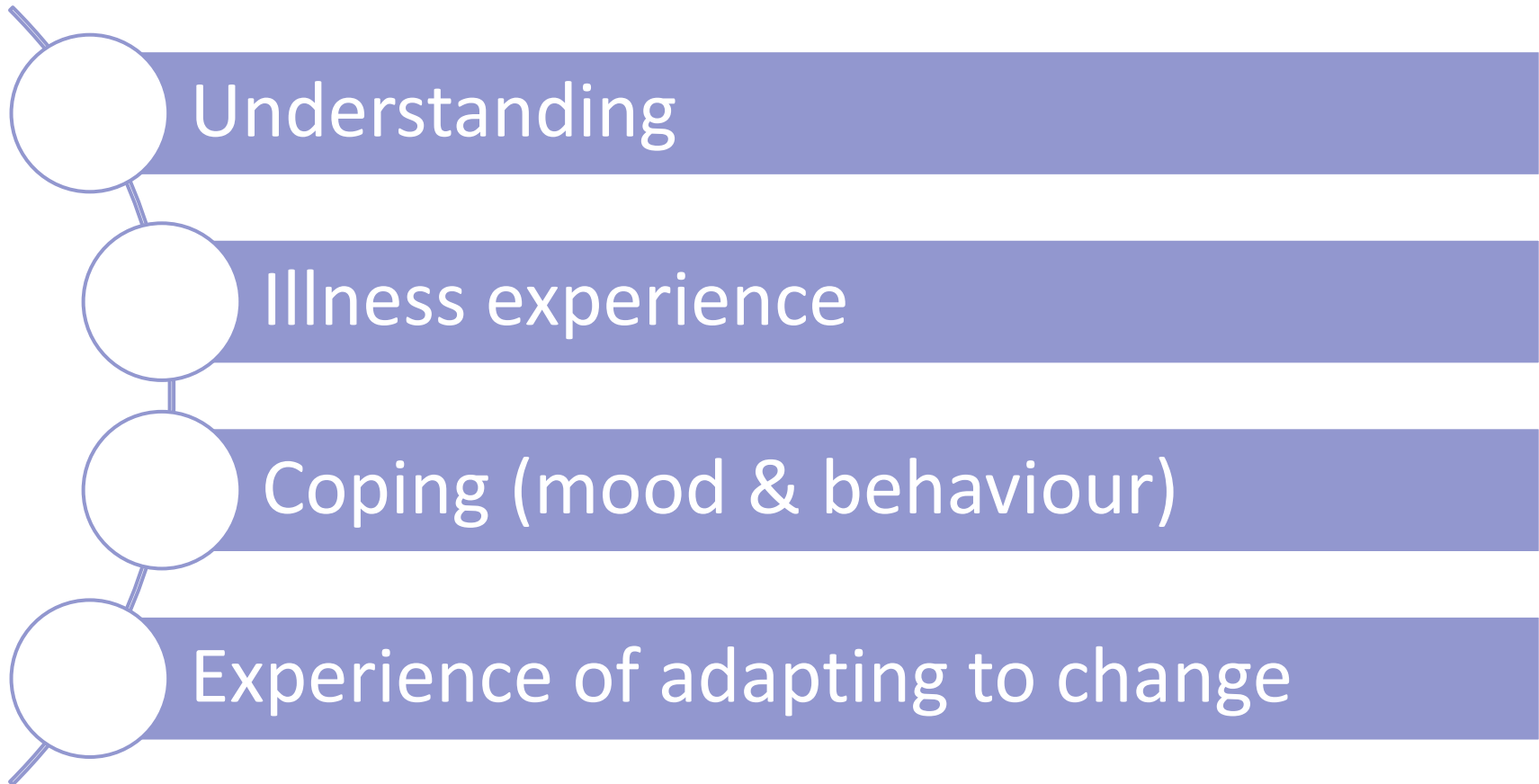
# What shapes our decisions?

- 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


# Dynamics of Decision Making



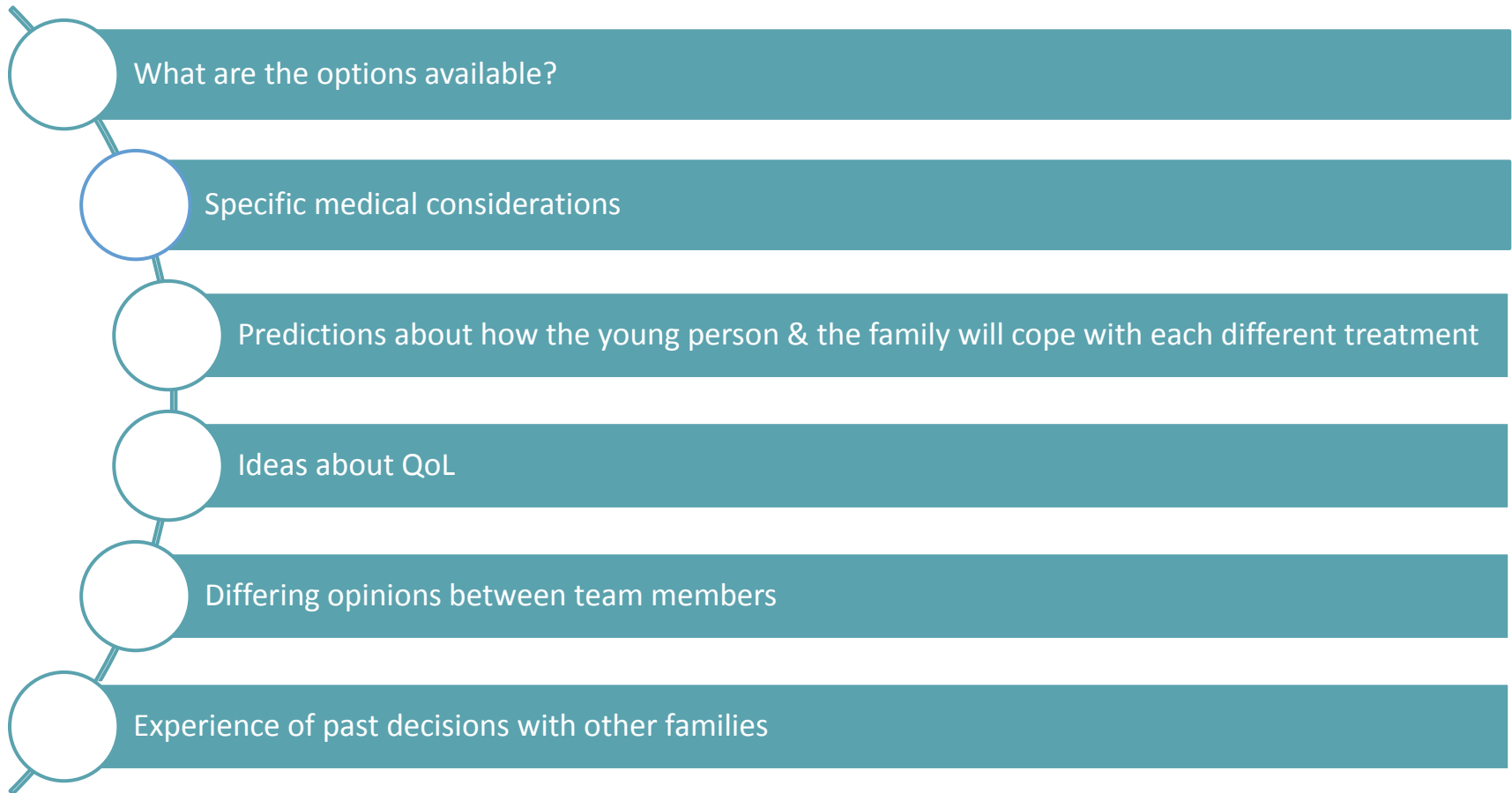
# Patient Factors



# Family Factors

- 
- 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



# Cognitive biases

- 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

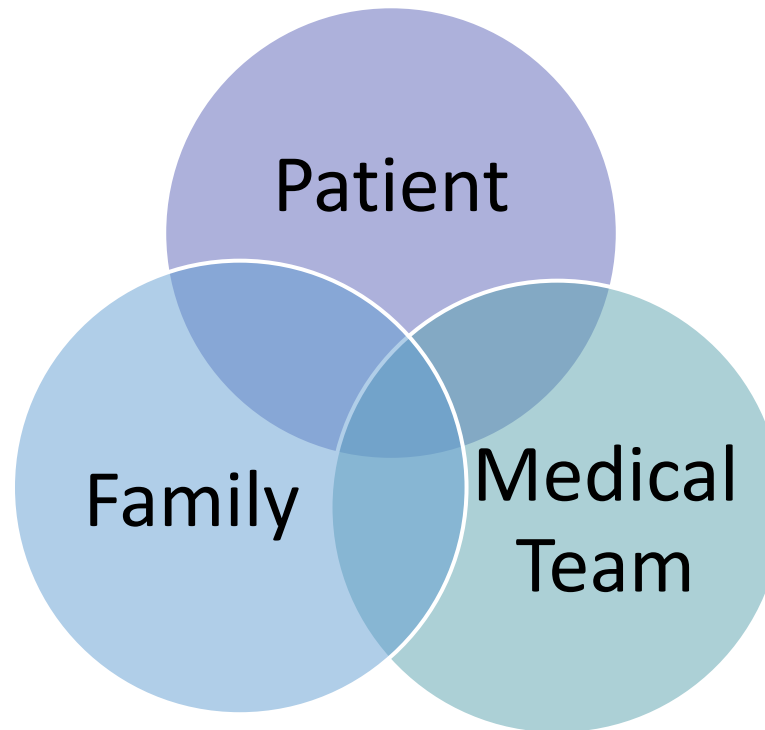
Understanding

Discussion with  
others

Feelings of  
control

Beliefs

Predictions



Cognitive biases

Assumptions

Judgements

Beliefs

Emotions

# GOSH

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

# 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

# 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).

# 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 he 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)

# 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





# Discuss.....



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