Difficult Decisions for Children: Who Should Make Them And How

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Case 1: Deepak

- 10 year old boy
- Gymnastics accident at 5 y, spinal cord transection – trache vented
- Evolving dysautonomia, abdominal pain, ileostomy
- Acute necrotising pancreatitis – recovering, but increasing stoma losses, considering LT PN
- Parents request stopping all treatment including IV fluids and LTV

Case 2: Sofia 2y

- Complex genetic condition with multisystem involvement – liver, kidney, pancreas, brain with organ failure (chronic and acute-on-chronic)
- Contraindications to some aspects of organ support
- Not candidate for transplant
- ACP discussion for
  - Continuing gradual deterioration
  - Acute organ failure
- Dad refuses to agree to any limitations of treatment

Four Principles

Beneficence and non-maleficence

Respect for autonomy

Justice

Gillon’s ‘moral mission statement for medicine’

- *“the provision of health benefits with minimal harm in ways that respect people's deliberated choices for themselves and that are just or fair to others, whether in the context of distribution of scarce resources, respect for people's rights, or respect for morally acceptable laws”*

Competent adults can consent to - or refuse – treatment

Can’t demand inappropriate treatment

Surrogates for (previously) competent adults

Autonomy and children

- But children are not ‘mini adults’
- Are they competent to make tough choices/ decisions?
- When can they consent?
- When can they refuse treatment?

Parents as surrogate decision makers

- Parental authority
  - Most common decisions in life

- Parental responsibility
  - Ensure child's interests

- Medical decisions – in child's interests, not whatever parents prefer, but…

Legal considerations

- The Children Act 1989, 2004
- UN Convention on the Rights of the Child (UNCHR)
- Mental Capacity Act
- Consent law, Gillick competence

Withdrawing or Withholding…LST

GMC guidance, 2002

RCPCH guidance, 2004, 2014

Guidance for situations where WD/WH may be appropriate – doesn't mean WD/WH should be carried out

Informed Competent Refusal of Treatment

Limited Quantity of Life	Limited Quality of Life
Brain death	Burdens of treatment
Imminent death	Burdens of illness/ underlying condition
Inevitable demise	Inability to derive benefit

Who are the experts?

Limited quantity of life	
Brain death	Objective, hence, medical professionals
Imminent death	
Inevitable death	

Who are the experts?

Limited quality of life	
Burdens of treatment	More ambiguous
Burdens of illness	
Inability to derive benefit	

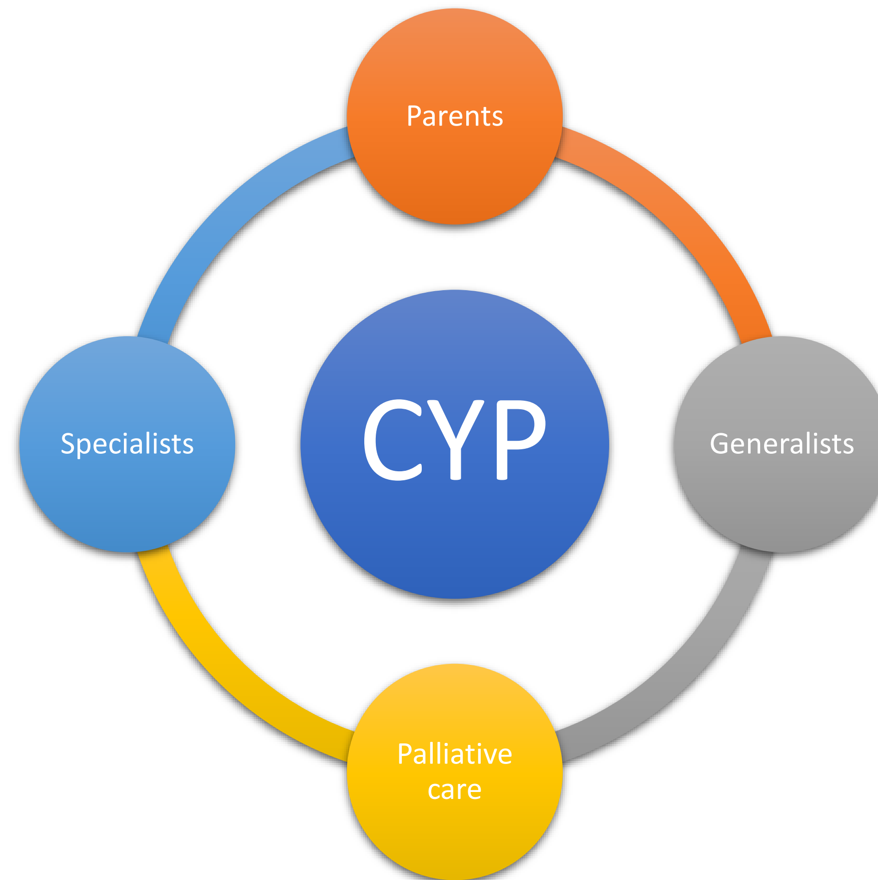
Judging quality of life

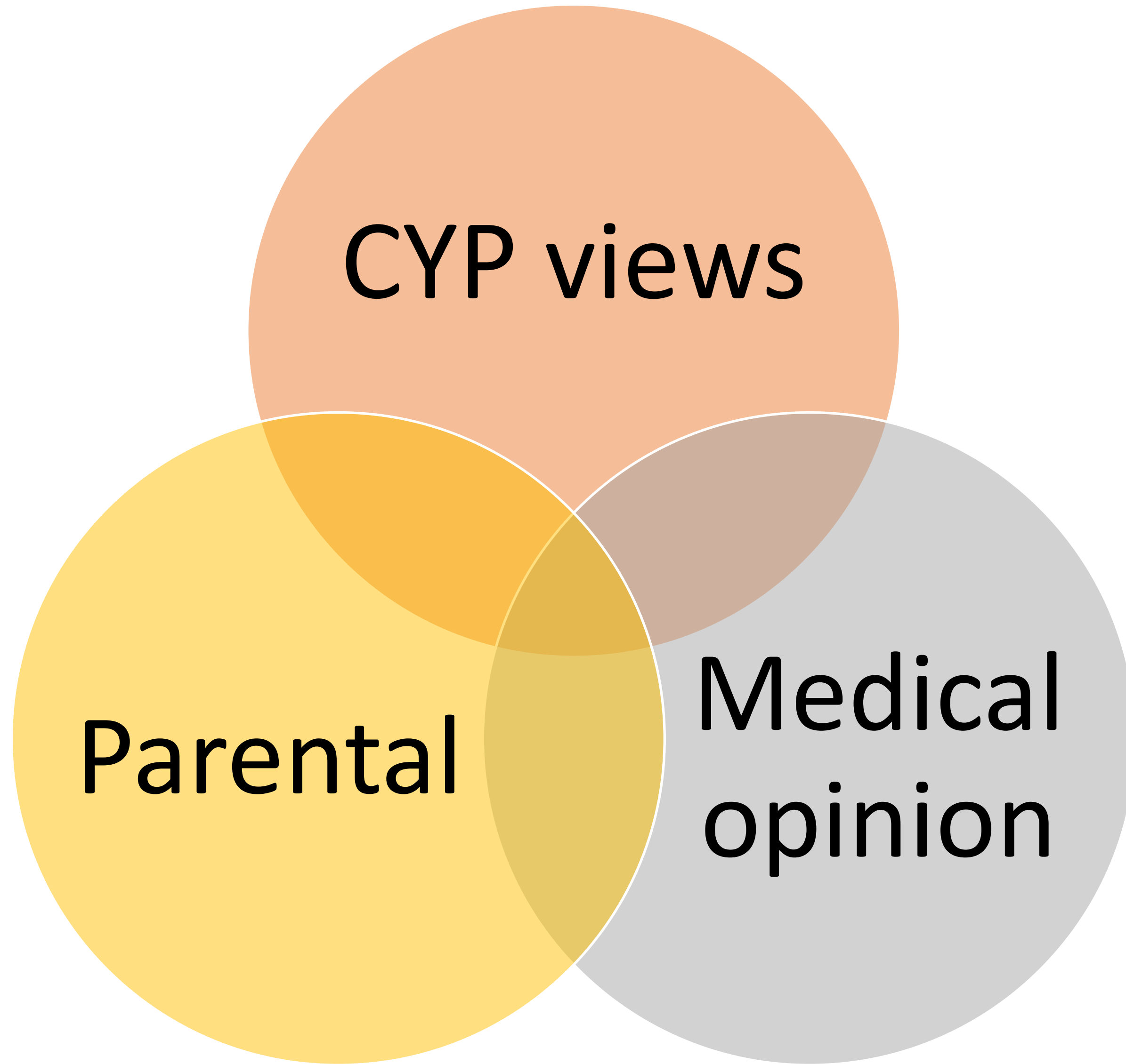
- Very subjective, value judgements
- Often impossible to make from snapshots in clinic/ PICU
- Parents know their child best!
    - their wishes,
    - their thresholds and tolerance,
    - their own (& sometimes their child's) perception of quality of life
- As experts in their own right, parents are our **colleagues**.

Decision making

- Defining the problem: ‘objective factors’
  - Framing, communicating
- Identifying goals and preferences: ‘subjective factors’
  - Not fixed (revisable), not always obvious or known
  - Explore aspirations, commitments and even character
  - CYP’s goals + family’s
  - Parents as protectors/ guardians

Working as a team to make decisions

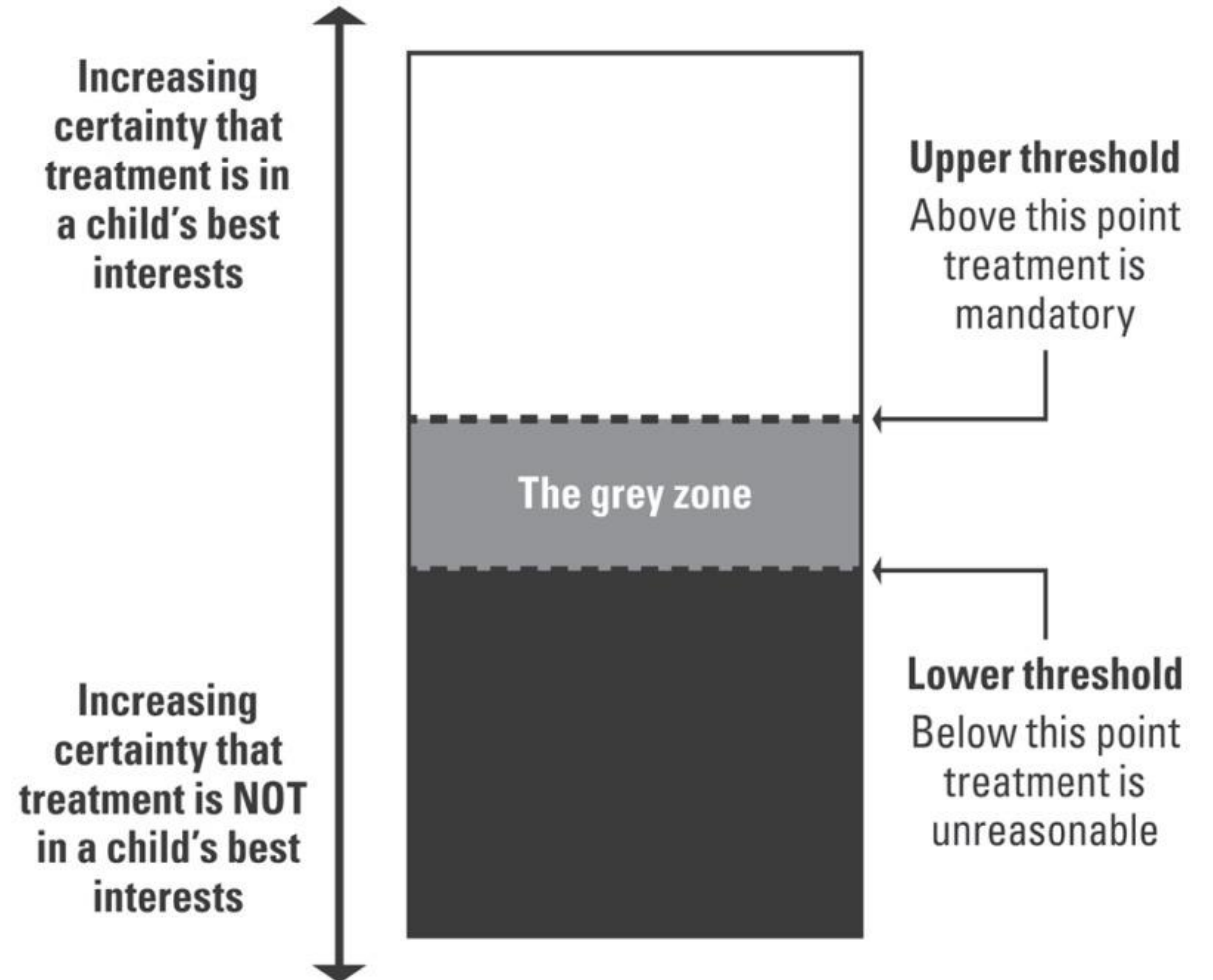




When does conflict arise?

The Zone of Parental Discretion (Gillam)

- Argues that 'best interests' could be too narrow a concept
- ' The Harm Principle'



Minimal Harm Threshold (Binik)

- <u>Overall</u> negative effect on substantive ‘goods’ – health, basic needs, intellectual stimulation, play, meaningful relationships, bodily integrity, and ‘happiness’.

- What about dignity? (especially at end-of-life)

ZPD not without its problems

- Narrow interpretations of ‘harm’
- Why accept less than optimal for some children?
- Who decides ‘threshold’ for ‘significant harm’? In which situations maybe harm acceptable?
- ‘Best interests’ is the legal standard
- Misinterpretation of ZPD >> parental desires/ preferences as default
- Isn’t ZPD regularly used anyway?

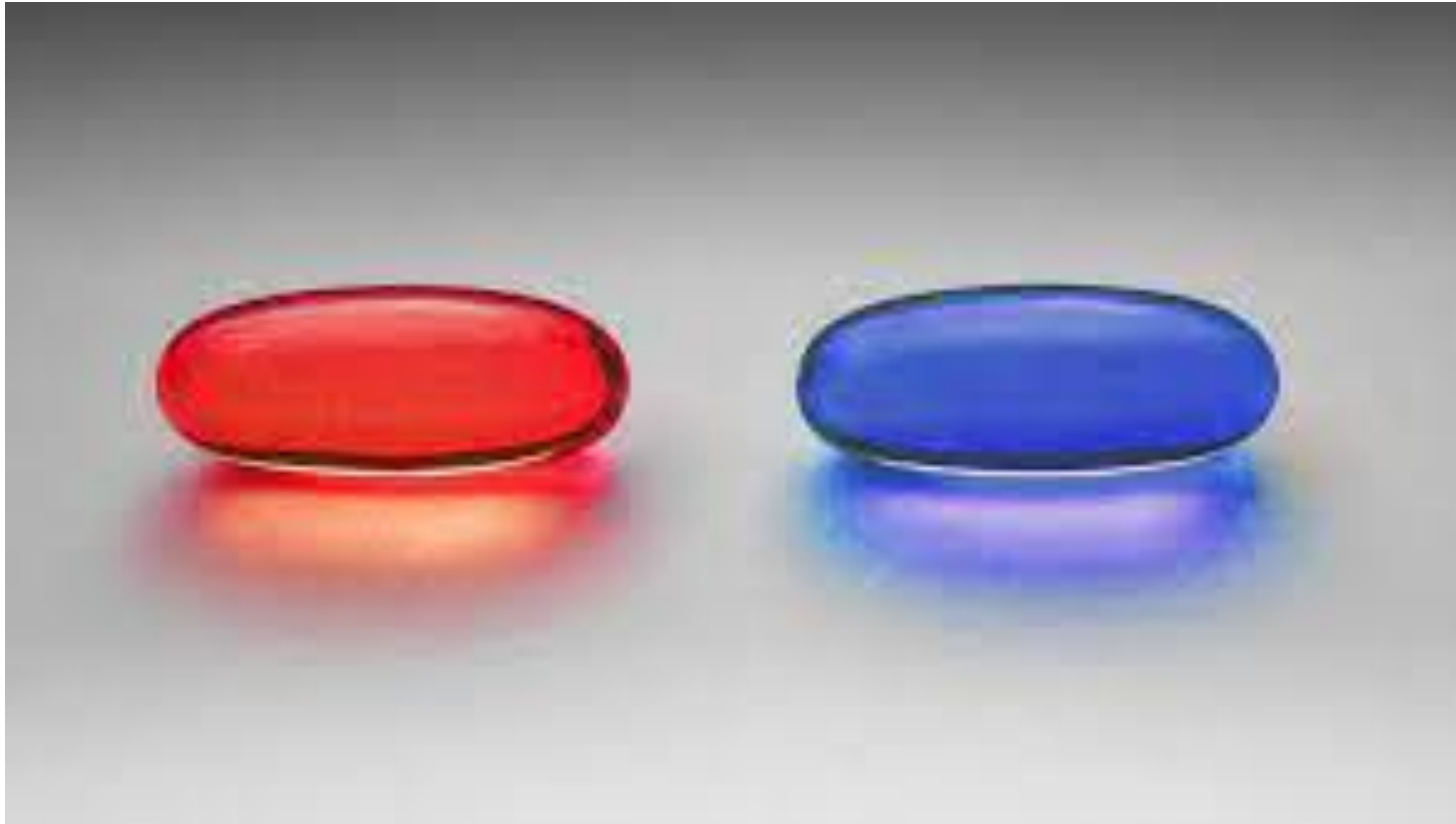
Almost always, all parties have the child’s interests at heart.
Why then does conflict arise?

- “Purported disagreements often turn out to be differences of what problems the various individuals are focussed on” (Feudtner)
- Parents’ instinct/ need to keep their child alive
- Lack of understanding/ lack of trust/ external influence
- Rarely malicious

- Profound disagreements >> entrenched views >> painful/ challenging/ worsening conflict

What helps? (Bluebond-Langner & Langner)

- Trust and rapport – honesty, realistic promises
- Communication – honest, timely information sharing
- Shared ‘reference point’ – gently ‘bring parents along’
- ‘Reframing loss’, avoiding simplistic, dichotomous labels
- Help balance ‘blended’/ conflicting goals



From Paternalism to Consumerism

(Gawande)

Sleight of Hand (Hain)

Don't say

- We will always do what you wish
- Do you want him to be resuscitated?
- Do you want her to have IV/IO/ ICU?

Do say

- We will always be honest
- Based on clinical info and your views,
  - Resuscitation (ICU/ IO) likely/ not likely to be beneficial
  - Risks/ burdens proportionate/ not proportionate

Don’t write

- “Parents do not want CPR/ ICU”
- “Should not have CPR”
- “Should have IO/ compressions/ drugs”

Do write

- “In this situation, it’d be/ won’t be appropriate”

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- How would you approach this situation?

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Summary

- Basic tenets of ‘interests’ - beneficence and non-maleficence.
- Professionals are experts on illness and treatment
- No obligation to provide non-beneficial treatment.
- Beware of making value judgements re: quality of life
- Parents are experts on ‘subjective’ aspects
- Listen to parents – treat them as colleagues.
- There may be more than one reasonable path (grey zone)

Easier said than done

- Involve the MDT (including palliative care and ethics)
- Continuous, iterative process: quick fixes are unusual
- Seek help from wider community incl. spiritual leaders
- Consult legal teams, PALS, ethics committees, mediation

- Courts?

Thank you

Any final questions/ comments?