

# Ethical decision making: Art or science?

Dr Julia Ambler

Julia@umduduzi.co.za



**umduduzi**

Hospice Care for Children

“In this extraordinary world of medical miracles, one thing has not changed; the complexity, challenge and pain of that most difficult of decisions:

is the treatment we are providing no longer in the best interests of the child?

There is no technology to help us here—only guidance, discussion and adequate time and information for truly shared decision making.”

Dr Hilary Cass, Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice

Larcher V, Craig F, Bhogal K, et al. Arch Dis Child 2015;100(Suppl 2): s1–s23.

# Defining life-limiting

- Conditions that will shorten a life span as there is no hope of cure
- By definition children with neurological disorders often fall into this group
  - Cognitive impairment (severe CP, degenerative conditions)
  - Without cognitive impairment (Duchenne's or SMA)
- The big difference AUTONOMY

# KEY PRINCIPLES

- **AUTONOMY**
- **BENEFICENCE**
- **NON-MALEFICENCE**
- **JUSTICE**

## BEST INTERESTS

Section 28: Bill of Rights

Highest net benefit among the available options that apply to any situation in which a decision has to be made regarding the health of the child (Beauchamp and Childress 2001)

Has to take into account physical, emotional, social, cultural and psychological needs  
Does not require what is ideal but what is reasonable (Kopelman 2007)

Distributive justice vs best interests

# CAPACITY

- Understand treatment options
- Able to weigh harms/benefits of options
- Able to understand consequences of decisions
- Governs process of informed consent

## Section 10: The Child Care Act

Every child that is of such an age, maturity, and stage of development as to participate in any matter concerning the child has the right to participate in an appropriate way and views expressed by the child must be given due consideration.

## TRUTH TELLING

- Duty to tell the truth
- Often lie to children
- We have a duty to help parents tell the truth
  - Disclosure is hard



## CONFLICTS OF INTEREST

- May arise when physician places interests of family above that of the child

Communications, like tumours, may be benign or malignant.

They may also be invasive, and the effects of bad communication with a patient may metastasize to the family.

**Truth is one of the most powerful therapeutic agents** available to us, but we still need to develop a proper understanding of its clinical pharmacology and to recognise optimum timing and dose in its use.

Similarly, we need to understand the closely related metabolisms of hope and denial.

*Simpson M quoted in Twycross 'Introducing Palliative Care'*

# Why is this difficult?

- Art vs Science
- Prognostic uncertainty
  - Fear to 'put one's head on a block?'
  - Fear of being wrong?
  - Fear of litigation?
  - Fear of difficult conversations?
  - Fear of stealing hope?
- Working in SILO's and poor teamwork
- Poor communication skills and lack of insight into one's own lack
- Who's decision is it?



# Who's decision?

- Parents have ethical and legal authority to decide on behalf of children who are unable, for whatever reason, to express preferences, unless they are clearly acting against the child's best interests.
- If they are unable, unwilling or persistently unavailable to make decisions on behalf of their child, the court's intervention should be sought.
- The wishes of a child who has obtained sufficient understanding, maturity and experience in the evaluation of treatment options should be given substantial consideration in the decision-making process.

# HCP Duty

- Act in the child's best interests *ALWAYS*
- Communicate with parents (and child where appropriate)
- Truthful, honest discussion which includes uncertainty
- Provide palliative care to support child and family, ensuring relief of suffering
- Not obligated to provide treatments that we do not believe will help the child

# What else can help us?

- Quality of life?
- Goal setting (and advance care planning)
- Examine our motives and self-reflection
- Seek out skills in communication, managing conflict and team work

# WHAT IS QUALITY OF LIFE (QOL)?

- QOL is complex ,multi-factorial and dynamic
- Often confused with value (intrinsic, unchanging)
- Individual's satisfaction or happiness with life in domains he or she considers important
- These dimensions include, but are not limited to,
  - Physical health
  - Material provision
  - Social, relationships,
  - Recreation

(Oleson, 1990)



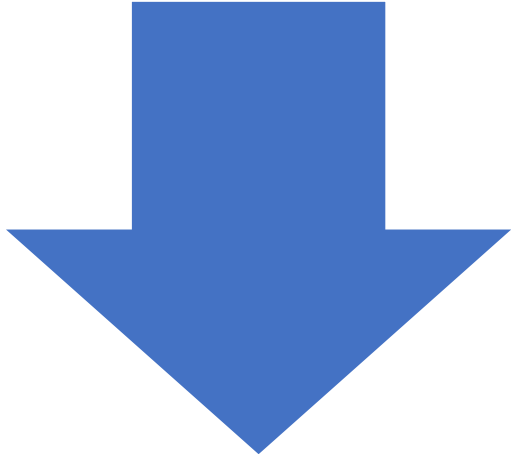


**Expectations  
Hopes, dreams**

**REALITY  
Present life style and experience**



# Quality of Life in Disability

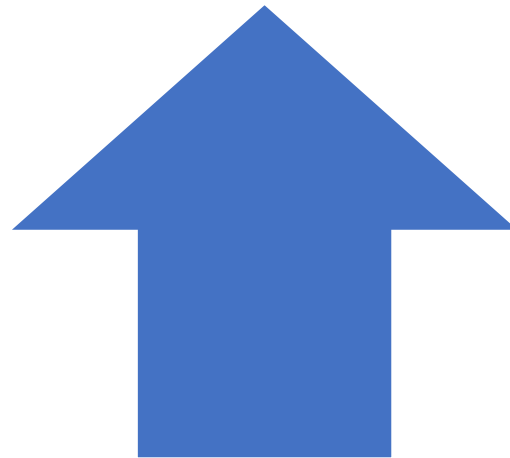


The negative impact of treatment in terms of pain, discomfort and distress.

Cannot confuse QOL with Value



The impact of treatments on the child's ability to communicate, experience awareness of those around them, experience pleasure, attain goals and be independent



# RCPCH 2015

2. Royal College of Paediatrics and Child Health Categories Includes categories where withdrawal and/or withholding of life-sustaining treatment may be ethically and legally justifiable		
Reason	Key determinant	✓
I. Life is limited in quantity	1. Brain stem death	
	2. Imminent death with physiological deterioration despite treatment	
	3. Inevitable death with no beneficial interventions	
II. Life is limited in quality	1. Burden of treatment outweighs potential benefits	
	2. Burden of the child's underlying condition causes suffering that overcomes potential benefits	
	3. Lack of ability to benefit	
III. Informed competent refusal of treatment		

# Futility

Intervention unlikely to achieve the goal of care

- Quantitative futility based on the odds of success
- Qualitative futility based on quality of life.

## Problems:

- How minimal must a chance of success be to be deemed futile?
- Classifications of futility based on assessments of patient quality of life inherently are biased
- Different clinicians and family's views may differ



# Bitter pills to swallow

- There is no legal, ethical or moral difference between withdrawing or not starting an intervention.
- **Any treatment** can be withheld or withdrawn (including Clinical Artificial Nutrition and Hydration)
- Two arguments –
  - Emotionally ‘easier’ to withhold rather than withdraw
  - Withdrawing implies a chance has been given and time to assess if it works and less chance of inappropriate withholding.

# GOAL SETTING

## What is the goal?

- **Cure** (with comfort measures alongside)
- **Trial of curative intervention** (will withdraw if not successful or side effects)
- **Rehabilitation to improve QOL**
- **Comfort** (supportive care)
  - AND (Allow natural death)
  - Planning for a 'Good Death'

# MOTIVES...



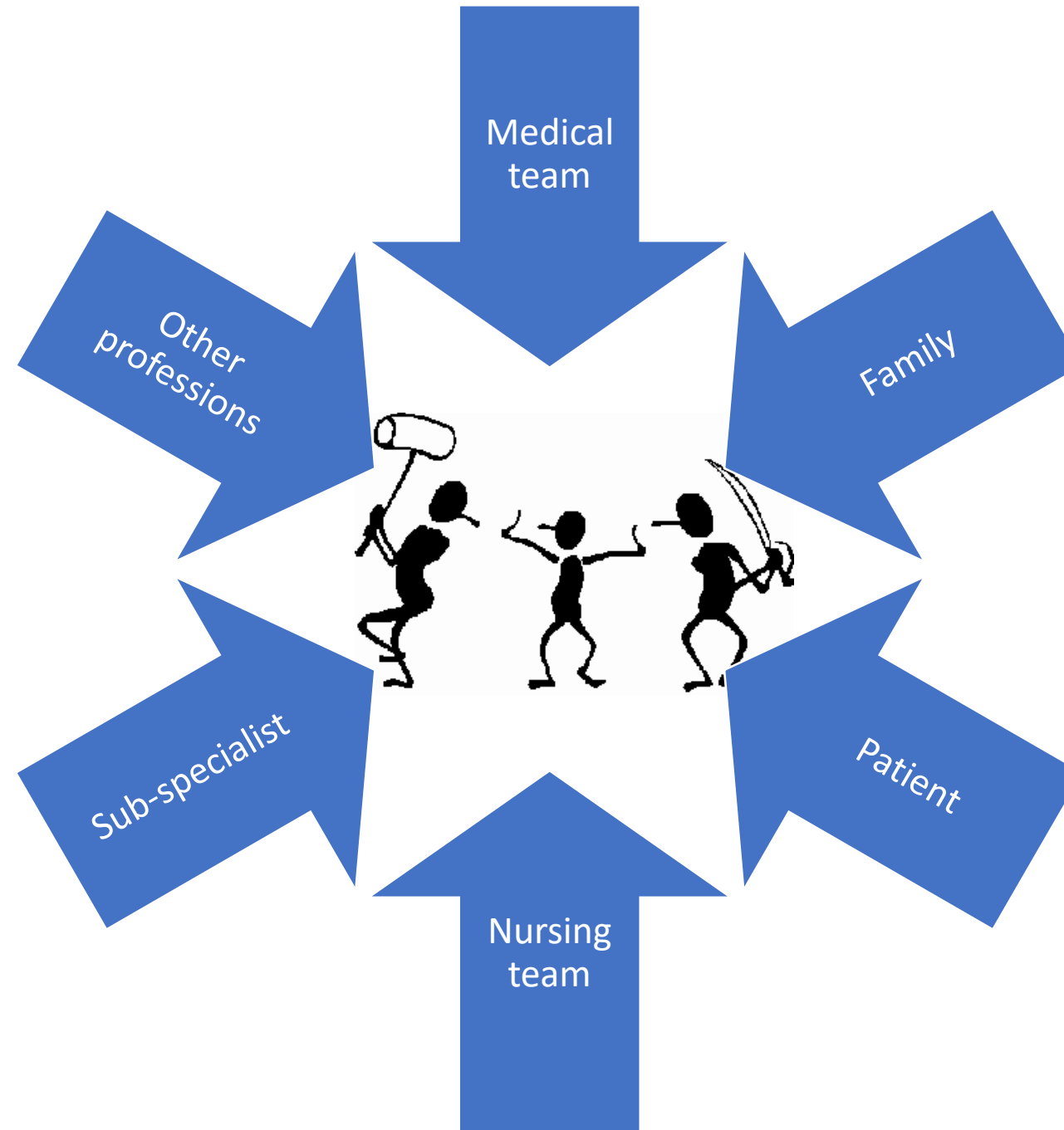
- ARE WE DOING THIS **FOR** THE CHILD OR **TO** THE CHILD?
  - A treatment may be medically possible but it may not help the child
  - Just because we can doesn't mean we should
- AM I DOING IT FOR MYSELF (THE HCP)?
  - I need to have at least tried...
  - I won't rest until I know I did everything I could

# The Team

- Greater openness between disciplines and grades will enhance mutual understanding of individual roles and responsibilities and heighten the sense of shared moral responsibility.
- The fact that some members of the team may have difficulties in 'letting go' should be acknowledged and addressed.
- Challenge the toxic hierarchy and develop mutual respect

# Conflict

Conflict arises!



# Preventing or resolving conflict

- Self-reflection and awareness
- Empathy, openness, honesty, humility to develop a trusting relationship with family
- Shared-decision making directly involving family in decision making without burdening them
- Team work - Include the whole team in difficult decision making – SING FROM THE SAME HYMN SHEET!
- Listen more than we speak

# What is Shared Decision Making?

- Shared decision making is both a philosophy and a process whereby the patient (parent/caregiver) and professional work in partnership to make decisions about care where there is more than one beneficial way forward.
- Shared decision making takes into account:
  - scientific knowledge and evidence base
  - patient autonomy
  - patient values and preferences

So what happens in paed's?

**REAL COMMUNICATION NOT INFORMATION SHARING**

# Seek the parent/patient voice

- What scares you the most?
- What do you pray for?
- When you lie in bed at night what goes through your mind?

## Then

- Share your concerns
- Gently share the facts, include the uncertainty, allow time to sit with the pain, the fear
- Share your ideas about the way forward



# Thank you



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