

Ethical aspects of decision-making in paediatric palliative care

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Key ethical principles in paediatrics

- Act in “best interests” of child
 - Promote/ maximise benefits
 - Minimise burden and risk
- Promote well-being of family
- Respect parents as decision-makers for the child
- Respect child’s (developing) autonomy
- Respect child’s privacy

Ethics in end of life care: basic principles



- Withdrawing and withholding medical treatment are ethically acceptable in some circumstances, even when the child is expected to die as a result
 - This includes artificial nutrition and hydration
- Withdrawing treatment that has been started is not ethically 'worse' than not starting treatment – the same reasons support both courses of action
- Prolonging life at all costs is not necessarily ethically appropriate – must consider comparative benefits and burdens to child

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Using ethical principles and tools to think through difficult situations

Things get difficult when:

- Principles clash
- People interpret principles differently

Two types of situations:

1. When parents and clinicians disagree
2. When the child is not being told or heard

1. Clinicians and parents disagree

Two aspects:

1. Different interpretations of benefit and harm
2. Ethical weight of parents' wishes/decisions for their child

Do clinicians have to do what parents say?

Basic benefits/burdens test

Ethical bottom line:

Any intervention should be reasonably expected to produce **more benefits than burdens** to the patient overall.

**** Consider burdens from child's perspective
(Burdens could include lost opportunities for good things)*

Check

Could the same benefits
be obtained by a
less burdensome method?

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Benefits and burdens at end of life



Most western-trained health professionals hold the view that continued life is not always and necessarily a benefit

- if the patient has no conscious experience, living longer may be neither benefit or burden to patient
- If the patient experiences suffering that cannot be relieved, living longer may be a burden rather than a benefit

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This is a value-judgement, and may not necessarily be shared by all families

Raises really fundamental questions of value:

1. What is the value of life? What gives meaning and worth to life? (for child, for parents?)
2. How much value does continued life have, when it involves suffering or distress, and death is inevitable in short to medium term? What is more important?
3. How much value does life have when there is no conscious experience?

Ethical weight of parents' decisions

Parents are the default decision-makers

Parents have a legitimate claim to be the decision-makers for their child, but within certain bounds

Parents' decisions are not final

There are ground for overriding them where:

- They would cause significant harm to the child
- When the resources used to provide what parents want would be disproportionate (ie unfair to others)

No obligation to provide treatment when you believe it is against child's interests

Clinicians do not have to provide (which they believe in good faith to be contrary to child's interests), even if parents want it

First check – is parents' decision well-informed?

Parents need

- information –
 - options, pros and cons of each (what each option will do to and for their child, levels of uncertainty), info about doctors' recommendation or opinion
 - Final outcome/ manner of death in each option
- to understand meaning and significance of all this
- To have opportunity and sense of freedom to make their own choice
- To have assistance/guidance in decision-making, if they want

Make a safe space real discussion

Leave time and emotional space for parents to move

2nd check – is parents' decision within Zone of Parental Discretion



Definition:

ZPD is the ethically protected space in which parents are permitted to make decisions for their child, even if these decisions are sub-optimal for the child – provided the decision won't cause significant harm

Basic idea

Reject / resist what parents want only when there is risk of significant harm to the child

Key question:

Is the parents' decision likely to cause significant harm to the child?

If yes, don't act on it.

Zone of parental discretion

Best interests of child

Decision will
produce *maximum* benefits

Zone of parental discretion
Accept parents' decisions

"good enough" interests

Harm

Outside parental discretion
Override/reject
parents' decisions

Child's best interests

“Best interests” is a summative judgement across all different aspects/ interests

It is a judgement about the overall balance of

- **Pros** – expected benefits, advantages
vs
- **Cons** – risks, burdens, disadvantages

The pros and cons cover:

- a range of domains – physical, psychological, emotional, etc
- Time periods – immediate, short term, long term

“Best interests” is not wholly a medical/factual/objective judgement – has a subjective values component

“Tahir”

- 10 y.o. son of Sudanese parents
- Father has returned to Sudan to ‘search for his brother’. Uncontactable. Has been absent and uncontactable for long periods before
- Mother (Samah) caring for Tahir and 4 other children. Another child died in the neonatal period in hospital in Sudan. Diagnosis uncertain.
- Samah’s first language is Arabic. She is able to speak in English but prefers to use an interpreter for complicated discussions.

Clinical Issues

- Cerebral palsy (severe birth asphyxia)
- Spastic quadriplegia: wheelchair dependent
- Vision impairment
- Can communicate using a board
- Gastrostomy feeds
- Requires regular suction as struggles with secretions
- Seizures: major seizure once a week, minor seizures multiple times a day

Recent events

- Recurrent aspiration pneumonia
- Chronic lung disease
- Admissions to ICU (on average) every 4 weeks for ventilatory support
- Tahir's overall condition takes a step down with each admission
- He is becoming less responsive, more lethargic, has lost weight, has a chronic cough.

Samah's perspective

- There has been a long history of tension between Samah and the clinical staff at the hospital.
- She is convinced that a miracle will occur and Tahir will recover.
- 'Where there is life, there is hope,' she says.
- Repeated efforts to discuss limitations of treatment (specifically intubation and ventilation).
- Samah will no longer engage in these discussions. She wants 'everything done' to prolong life. Suffering is not a consideration for her. Life is the most important thing.

Samah feels like Tahir is being treated as a second class citizen because he is disabled.

In fact, she has said to one of the social workers that staff are trying to 'kill him' because she has not agreed to limitations on treatment.

She says that despite his disability, he is much loved and lives a worthwhile existence.

Staff perspective

- Many staff members feel they are 'not providing treatment that is in the child's best interests' and wish to limit interventions (specifically, intubation and ventilation)
- Although the question of resources is not raised directly, it is alluded to.

Ethical questions

Is it ethically appropriate to decide against intubation and ventilation for Tahir's next respiratory episode?

- Is parental consent needed for this?
- If Samah does not agree, can treatment be limited anyway?

Further developments

- Concerns about loss of skills and escalating seizures
- Referred to a neurologist who discovers Tahir has a neurodegenerative in addition to his CP.
- Tahir's condition deteriorates further.
- Intubation and invasive ventilation deemed 'futile' by consultants i.e inflicting harm, providing no benefit
- It has been decided that he will not be intubated and this has been communicated to his mother.
- He is on the ward receiving BiPAP and is struggling.

- The palliative care physician discusses symptom management with Samah and when he mentions morphine, she becomes alarmed and insists that this must not be given to her child.
- She says she, 'knows what that is used for'. She tells him she has seen it used in Sudan and becomes distressed, saying that the hospital staff are trying to kill her son.
-
- She prepares to leave the hospital with Tahir.

Ethics questions #2

- Is intubation and ventilation 'futile'?
- Should the opioid be given?

What happened?

- Tahir struggles with respiratory distress
- Some staff feel strongly that the opioid should just be given. Other staff worry that if that happens, Samah will take Tahir home where he will not receive any clinical support at all

- That night, one of the nurses says to Samah, 'We can see how much you love Tahir and how hard you are trying to do the best for him.'
- Samah cries and cries, then says, 'I can't watch him breathing like this any more.'
- After further discussion, an opioid is commenced and Tahir dies peacefully on the ward 36 hours later

Summing up

Ethics is mainly about the process of decision-making:

- identifying ethical important situations when they arise
- recognising your own perspective and beliefs
- articulating the ethical values and considerations at stake
- identifying options for how to proceed
- making a decision for which you can give reasons:
 - reasons refer to values
 - reasons appropriately take into account practicalities
 - reasons explain why you took this course of action,
not other possible ones

**** there may be more than one ethically appropriate
course of action in a given situation**

Case 2: Baby J

- 4 month old with polymicrogyria in one cerebral hemisphere suffering severe, life-threatening apnoeic seizures 2-4 times a day. These require high level airway support (nasopharyngeal tube) and bag and mask ventilation for up to 30 minutes. Child becomes severely bradycardic during some of the seizures.
- The seizures have been resistant to multiple anticonvulsants and the ketogenic diet. The seizures are coming from both hemispheres, with the majority from the left hemisphere. Surgical treatment not an option
- J has been in hospital all of his life. Between seizures, child is sleepy much of the time but is able to interact. He has a NGT in place because ability to feed is limited. He has bilateral severe hip dysplasia with dislocated hips. Long term prospects are poor. There is a high risk of death during seizures even with support described above. High risk of significant disability. At present, no realistic prospect of discharge because seizures could not be managed by parents or carers.

- Parents aware of prognosis. Father feels that this is not a life worth living for his child. Mother also feels this way but has held on to some hope that things would improve. Her hope is diminishing over time.

There are limits already in place in that the child is not to be intubated, have cardiac compressions, inotropes, CPAP or BIPAP or go to ICU. Parents and treating team both agreed on this.

The treating team is now of the view that interventions such as airway insertion and bag and mask ventilation may not be in the best interest of the child due to the severity of his condition with poor prospects for long term survival; these interventions simply prolonging a life of extremely poor quality. Parents distressed and don't know what to do.

Case 3: Child P

5 year old girl, near-drowning. Severe hypoxic brain injury, ventilated in ICU for 2 weeks, now minimally responsive, several failed attempts to wean off ventilation ie ventilator-dependent. No prospect of recovery from this situation, but could live long-term if ventilation continued.

Parents are separated, P has been living with mother. Parent have been asked whether they want ventilation withdrawn. Initial reactions very different. Mother yes (doesn't want tracheostomy, too brutal, thinks life would be awful for her daughter) , father no (wanted home ventilation, must do everything for P, his mother travelled from Ireland to support him in this. She says it would be a sin to stop ventilation – religious obligation to continue.

After several days, P's mother agreed to continued ventilation.

P goes home on ventilation. Mother, father and grandmother trained to care for her. Modifications made to mother's house. Mother's friends come to assist on organised roster.

2 months after going home, parents indicate that they want to stop ventilation. No medical sign of improvement in P's status – presumably still ventilator-dependent, would be expected to die quite soon if ventilation ceased