



To feed or not to feed, that is the question...

Foregoing medically
provided nutrition in
palliative care situations in
children...are we ok?

The Evolutionary Problem

- “the provision of nutrition is one of the most fundamental things that parents (or medical professionals) do for children”
 - Dr Dominic Wilkinson, 2012

“Medically Provided Nutrition”

- Hydration/ nutrition via
 - Nasogastric tube
 - Intravenous/ Central venous Line
 - Gastrostomy (PEG)
 - Jejunostomy

Emotive Language

"starving"



"force feeding"



"eating"



Beneficence- to only do good

- Artificial Feeding promotes;
 - Healthy weight
 - Growth
 - Prevention of hunger
 - Gut motility
 - Nourishment satisfaction
 - Wound healing
 - Resource for medication administration

Non-Maleficence; to do no harm

- Medically provided nutrition can cause;
 - Vomiting, Nausea, Bilioussness
 - Aspiration Pneumonia
 - Gut spasm
 - Tumour growth
 - Malabsorption
 - Diarrhoea
 - Constipation
 - Excess secretions

- “Suffering to be fed”

Burdens outweighing Benefits

- American Academy of Pediatrics;
 - *"treatment decisions regarding an infant should be based on the judgement that the infant will net benefit".*
 - *"nutrition may fail to benefit a child or create a level of burden that cannot be justified by whatever benefit might accrue".*
- Point to ponder; why do we fluff around so much now with PEG-Jej without considering that they just not longer can be fed??

Nature of death

- Withdrawal timeframe to death; 10-14 days (Cranford 1995), 1-37 days (Siden 2010)
- Suffering- few Paed studies but dialogue of peaceful deaths
- Alleviate hunger/distress with sedation, sucrose, mouthcare
- Parental/Professional distress
- Visual wasting/ emaciation

Compassionate Questions

- Is there presence of an unrelenting, burdensome illness?
- Does medically assisted feeding prolong and add morbidity to the process of dying?
- Will nutrition offer any benefit?
- Will it risk any harm?
- Can we keep the child comfortable without medically assisted feeding?
- Is all of the above assessed in the best interests of the child?

Responsibilities

- Clear assessment and discussion
- Refocus goals of care
- Parental agreement
- Ethical review/ discussion
- Comprehensive palliative care
 - Sedation
 - Mouth-care
 - Clothing
 - Parental support
 - Pressure area care

Case Study

- Robyn is 13 years old, he has severe CP, a poorly controlled seizure disorder, and his adolescent growth spurt has made him severely scoliosed to the left and very thin.
- Over the past few months he has had increasing episodes of vomiting his gastrostomy feeds and associated aspiration pneumonias and moaning.
- His parents have tried many different feeds and regimes, antiemesis and positioning.

Case Study

- Eventually they state that they do not think he benefits from feeds and that they are hurting him by feeding him.
- What needs exploring here?
- What would you be planning?

Compassionate Questions

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Are we OK?

“Some say withdrawing medically provided hydration and nutrition is akin to withdrawing any other form of life support. Maybe, but that is not how it feels.

Anon, BMJ 2012

“This process is necessarily difficult”

What must we do

- Talk as a team (and with related teams)
- Get support eg; Ethics opinion
- Be clear get perspective
- Ramp up the self care; rebalance, 'carve out more sacred downtime" Wolfelt
- More team support activities
- Respect individual clinicians choices about participating in care/decisions
- Remain focussed on the reason, the burden otherwise to the patient



Questions?

Comments?

Disagreements? Sobs?

Statements of Flattery?

Ok you can leave now....!

References

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