Nutrition & Anorexia

Beyond the Withdraw/Withhold Paradigm

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Latitude 42° N; Longitude 12.5° E
Length 1,185km

Latitude 42° S; Longitude 171° E
Length 1,600km


· CAMPANIA
· PUGLIA
· LAZIO
· TUSCANY
· LIGURIA
· EMILIA
· LOMBARDY
· VENETO


Kaitaia
Whangarei
North Island
Auckland
Tauranga
Hamilton
New Plymouth
Gisborne
Napier
Hastings
Tasman Sea
Wanganui
Palmerston North
WELLINGTON
Nelson
Wesport
Blenheim
Hokitika
Greymouth
Kaikoura
Pacific
Ocean
South Island
Christchurch
Ashburton
Timaru
Oamaru
Gore
Dunedin
Invercargill
Stewart Island
300 km
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What could be covered?

Nutrition

- assessment
  - detect malnutrition & complications
- requirements
  - calories, fat, protein, fluid
- interventions

Feeding

- choice of route
  - oral, NG, PEG, TPN
- choice of regimen
  - bolus vs. continuous
  - night vs. day vs. 24-hr
- home support & monitoring
- problems & complications

What could be covered?

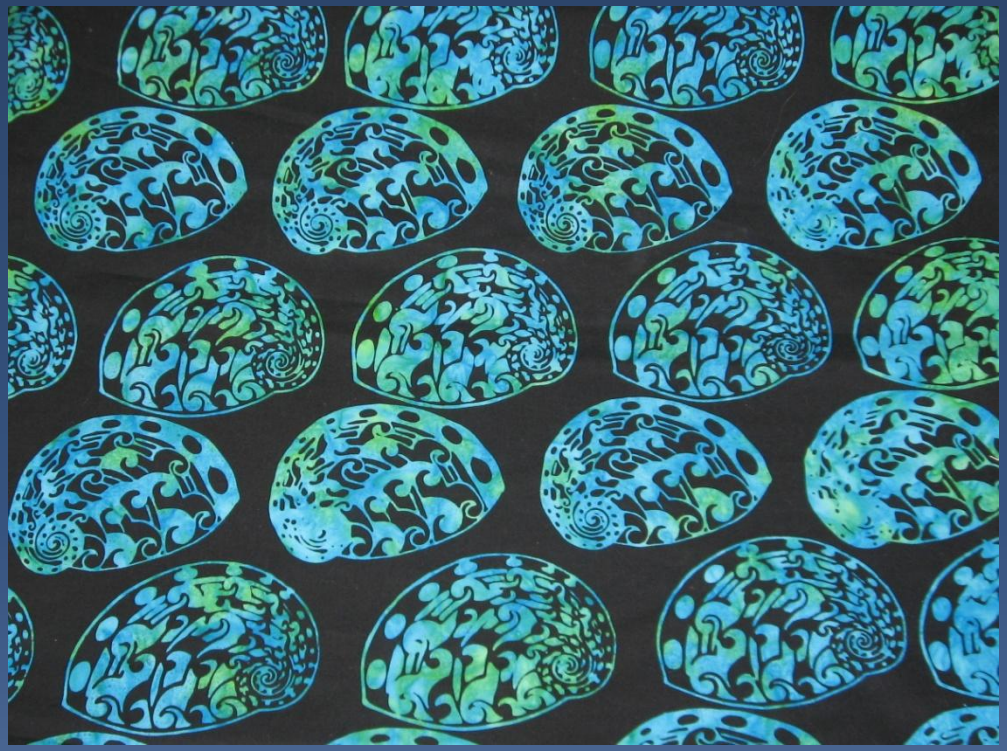
Anorexia

- pathophysiology incl. cachexia
- aetiology
- evaluation
- integrative management
  - non pharmacological
  - pharmacological

Issues

- meaning
- psychological
- spiritual/existential
- ethical
- decision-making
  - withhold/withdraw
- effect of non feeding
  - on family
  - on healthcare professionals

What will be covered?



Case 1

- 10 yr old boy with non specific intestinal failure & intractable diarrhoea
  - not eligible for transplant
- TPN dependent since birth
  - TPN-related liver disease
  - IVC & SVC thromboses
  - extremely difficult vascular access; CVL in azygous vein
- gastrostomy tube *in situ*
  - use worsens diarrhoea
- no longer wants TPN
  - supported by parents
- discussions around NOT replacing line when it fails
  - GI specialist worried about death from malnutrition
- CVL fails 1 month later

Withhold/Withdraw

- well trodden & familiar path in PC
  - "pasta & amatriciana sauce" conversation
- ??expectation that PC will support *negative* action i.e. withdraw/withhold
- no matter what position statements say, it is a difficult/stressful clinical conversation

Position Statements (in short)

- if able to orally feed then provide food & fluids
- if provided medically = medical intervention
  - decision to w/w as per other medical interventions
- decision-making based on providing net benefit
- primary focus should be interests of child
- while morally permissible it is not morally required

Who?

- permanent lack of awareness & ability to interact with environment
  - persistent vegetative state
  - profound neurological insult
- very limited survival from birth or condition
  - renal agenesis
  - severe GI failure
- food or fluid prolongs or adds morbidity
- actively dying

AAP, FRACP, RCPCH, BMA

Literature

- relies on ethical position; largely consensus based
- medically assisted hydration & nutrition
  - studies published do not show a significant benefit for use
  - insufficient good quality trials to make practice recommendations

Good P et al. Cochrane 2014

- multicenter, double blinded, placebo RCT (n = 129)
  - hydration 1L/day vs. 100mL/day did not improve symptoms, QoL or survival

Bruera E et al. JCO 2013;13(1)

Queenstown, NZ

Como, Italy

Parental influences

- interview of 40 parents with child in PICU imagining withdrawal situation
- decision affected by
  - child suffering – 64%
  - QoL – 51%
  - physician estimate of prognosis – 43%
  - financial factors – 7%
- qualitative analysis
  - QoL
  - suffering
  - ineffective treatments
  - faith
  - time
  - financial considerations
  - general rejection of withdrawing life-sustaining therapies
  - mistrust/doubt of physician(s)
  - reliance on self/intuition

Michelson KN et al. APAM 2009;163(11)

Parental perspective

- interview of 11 parents where child had died after deciding to forgo ANH
- all satisfied with decision
- death considered peaceful & comfortable

- decision based on
  - perceived poor QoL of child
  - feed intolerance contributed to perception
- however
  - all parent's had doubts & questions about decision
  - benefited from ongoing reassurance from clinical team

Rapoport A et al. Pediatr 2013;131(5)

HOPE/SPERANZA

Case 1 – What happened?

- CVL not replaced
  - eating as tolerated
  - 70 mL/hr pedialyte
- good days & bad days
- x3 large, watery BM per day
- maintained weight around 20 to 21kg

- 1-yr later gastrostomy removed as not needed
- moved out of Auckland

- 3 years later (present day)
  - same unrestricted diet
  - weight around 24kg
- complications
  - liver disease improved
  - mineral (Ca^{++}, Mg^{++}, Zn^{++}) & vitamin D deficiencies
  - bone pain
- new gastrostomy suggested by GI service
  - counter to desire of family
  - communication issues develop with local service

Whale Bay, Northland

Praiano, Amalfi Coast

Case 2

- 17yr old male, DMD
  - wheelchair dependent
  - good cardiac status
- poor physical strength
- musculoskeletal pain
- fatigue +++
- anorexia & weight loss
  - 8kg over 6mo

"I didn't know anything about weight loss to do with DMD and that maybe you could have alternative food. I didn't know about it until we were having to make a decision about whether we did it or not."
Mother

He does not want artificial nutrition!

- parents want this

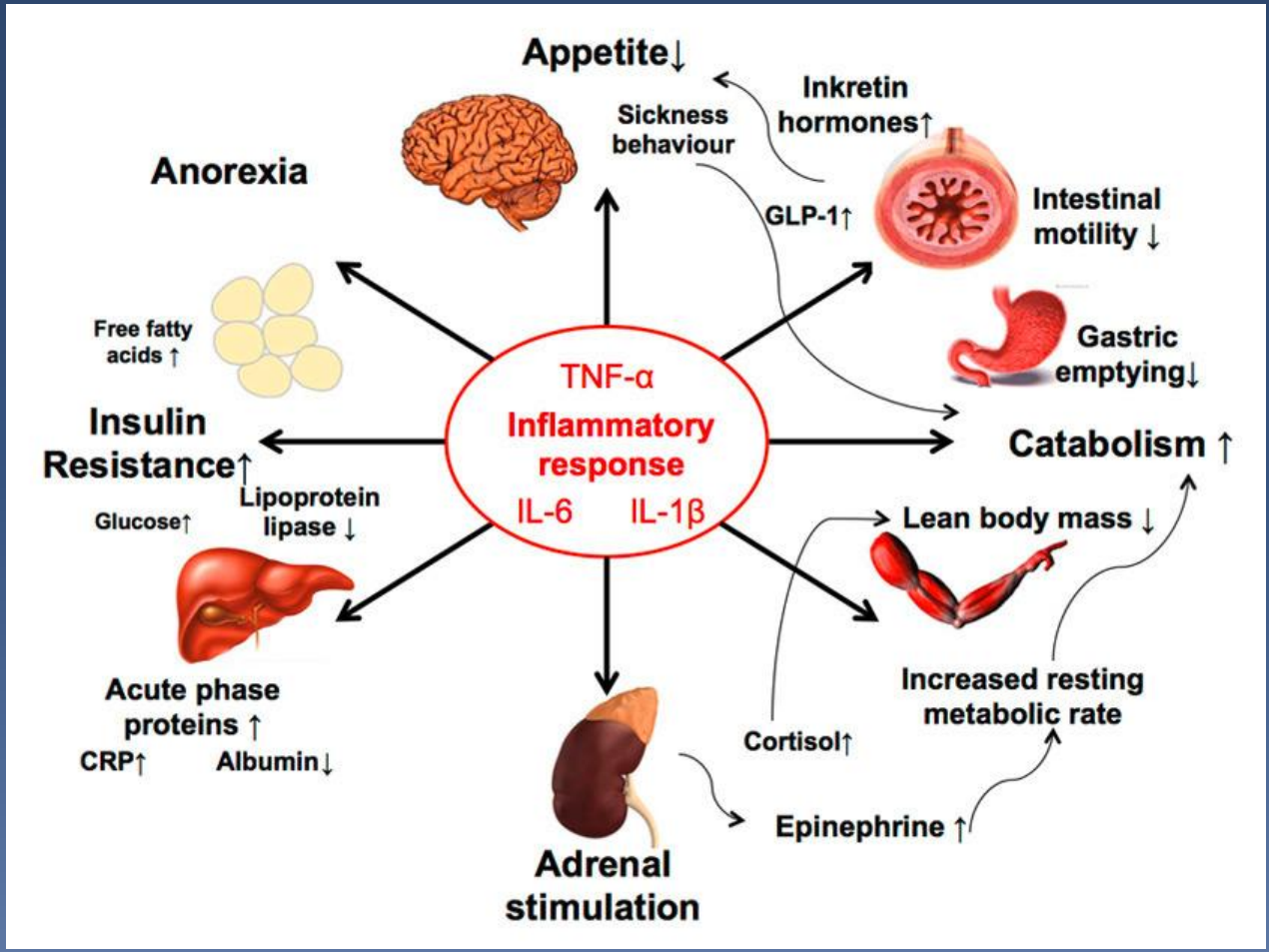
Anorexia – loss of appetite

Multi-factorial interplay of neuropsychoimmunoendocrine system

Cancer
ESRF/CRF
Chronic lung disease
Chronic heart disease
Neurodegenerative disease

<u>Consider</u>

Chronic pain
Chronic nausea
Depression and/or anxiety



What to do?

- proactively address
- provide information & education
  - do not underestimate effect
- anticipatory exploration of emotional & spiritual issues
  - offers forum to air beliefs that may hinder therapeutic relationship
- strategies that may increase food intake
  - offer favourite foods
  - eliminate dietary restrictions
  - reduce portion sizes but increase no. of meals
  - make food look more enticing
  - avoid disliked food smells

Psychological factors

- extension of exploring emotional & spiritual issues
  - encourage child & family interaction to reduce psychological distress
  - support family to distinguish what they can & cannot control i.e. disease progression vs. helping their child find comfort
  - explore emotional components & meaning of the child not eating & losing weight
  - assess the impact on child & family
  - assess the quality of life of child & family

Case 2 – ?Artificial nutrition

- discussions on pro's & con's for PEG held over several days
  - feeling under pressure to have operation
  - believed operation would shorten his life
  - worried about change in his appearance
- mental health
  - anhedonia
  - frequently tearful
  - increased sleep
  - isolating self from peers
- agrees to PEG
  - reports not feeling coerced
  - straight forward placement under radiological guidance

He is depressed

Remember

- nutrition in children with neurological conditions is likely to be sub-optimal
  - 38% underweight
  - 56% choked on food
  - 22% vomited
  - 20% parents described feeding as unpleasant

- 64% had never had their feeding or nutrition formally assessed

Sullivan PB et al. Dev Med Child Neurol 2000;42(10)

Other therapy options

Pharmacological Agents		Pharmacological Agents	
Anabolic agents	Testosterone and analogues Growth hormone	Cytokines	IL-10 IL-12
Anti-cytokine agents	Antibodies Antisense therapy Pentoxifylline Thalidomide	Hormones	Insulin Melatonin Erythropoetin
Anti-depressants	Mirtazepine	Metabolic inhibitor	Hydrazine
Anti-inflammatory agents	Ibuprofen Indomethacin	Porcine extract	
Anti-psychotic agents	Olanzepine	Prokinetic agents	Metoclopramide Cisapride
Appetite stimulants	Progestational agents Corticosteroids Cannabinoids	Serotonin antagonists	Cyproheptadine Ondansetron
Beta-adrenergic agonists	Clenbuterol	Suramin	

TPN

- specific benefit
  - enteral not an option
    - bowel obstruction, short bowel syndrome, etc
- death more likely from starvation than disease
- life expectancy allows reasonable trial

- good self-assessed?? QoL
- prolonging life consistent with goals of care
- aware of risks & accepted
- can be done safely at home
- monitoring
  - electrolytes etc
  - response & clinical course

Case 2 - outcome

- 10 mo. later – feeling the best he had in years
  - improved weight
  - improved energy
  - less fatigue
- mood improved on SSRI
- existential distress continued
  - revolved around loss of peer group & lack of companionship
- after 1yr – not using PEG; maintaining calorie intake orally

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COMMUNICATION/COMUNICAZIONE